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ABSTRACT

This report describes the evaluation of the Centers for Independent Living Program, required by the 1984 amendments to the Rehabilitation Act of 1973, Part B. The evaluation, which assessed the impact of the centers in increasing opportunities for disabled individuals, was based upon data acquired through mail survey of 156 centers funded in 1984-85; 2,700 disabled consumers of center services, and 180 local community agencies; and on-site interviews with consumers, center staff, and community agency representatives in 40 centers. Among findings were that more than 48,000 disabled persons were served by the 121 responding centers; that 75% of the 990 responding consumers were severely disabled; that the centers provided a wide range of services (i.e., advocacy, independent living skills training, peer counseling); that Part B funds comprised 44% of center budgets with three-fourths of budgets going to direct client services; and that over 90% of consumer respondents reported gaining from center services. Following the executive summary and introduction, this report presents an overview of the program, characteristics of center consumers, services provided, consumer outcomes, consumer participation, descriptions of the development of community options for independnet living, and information regarding management of the centers. Six appendices present such information as the development of evaluation standards, study methodology, and a summary of performance on each evaluation standard. (DB)

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COMPREHENSIVE EVALUATION OF THE TITLE VII, PART B OF THE REHABILITATION ACT OF 1973, AS AMENDED, CENTERS FOR INDEPENDENT LIVING PROGRAM

FINAL REPORT

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PREFACE

This report presents the findings of the evaluation of the Title VII Part B Centers for Independent Living Program which is the first such national evaluation of the independent living centers. It was conducted in response to Congress' mandate to describe and assess the impact of the centers in increasing opportunities for individuals with disabilities. Congress has long recognized the importance of disabled consumers in this program and thus mandated their involvement in the development and conduct of this evaluation. The measures of "standards" upon which the evaluation is based evolved from the efforts of independent living centers, disabled individuals and other knowledgeable actors around the country, and represented the first nationwide effort to develop a consensus about defining and setting priorities for independent living services. These evaluation standards embody a vision of independent living centers that reaches beyond the guidelines established by Congress and reflects the advocacy and self-help philosophy of the independent living movement. The evaluation involved collection of data from the centers themselves, consumers of their services, and local community agencies. The instruments used for data collection were designed to collect the data specified in the evaluation standards. Thus, this evaluation seeks to understand how the centers perform in the context of the broad vision encompassed by the evaluation standards, as well as in the context of the Congressional mandate.

The evaluation team wishes to gratefully acknowledge the contribution of time and energy made by the centers themselves in providing the necessary data, arranging visits and interviews with community agencies and consumers, and pulling together the consumer and community agency samples for the mail surveys. We'd also like to thank our tireless Advisory Committee members for the long hours of meetings and review of written materials that provided us with invaluable guidance. In addition to the members of the formal Advisory Committee we'd also like to thank Suzanne Choisser, Rod Pelton, Tony Cavataio, James Moss and Albert Rotundo of RSA, Sue Betka and Art Kirschenbaum of OPBE, Mike Harold and Greg Marsh of OSERS, Bill Messori of Rhode Island VR, Sandra Perrino and the staff of the National Council on the Handicapped, and the many other knowledgeable individuals who provided us with guidance and input.

EXECUTIVE SUMMARY

INTRODUCTION AND STUDY APPROACH

The 1984 amendments to the Rehabilitation Act required a comprehensive evaluation of the Title VII, Part B of the Rehabilitation Act of 1973 Centers for Independent Living Program. The purpose of the program is to provide independent living services to persons with disabilities and their families to increase options for such persons to live independently in the community, to improve the quality of life for disabled individuals and to maximize their integration into the mainstream of society, and whenever possible, to contribute to the vocational outcomes and gains that vocational rehabilitation (VR) services seek to achieve.

During the first phase of the evaluation, measures -- or "standards" -- were developed to reflect 11 specific areas of interest to Congress. The process for developing the evaluation standards ensured broad input from centers for independent living, consumer advocacy organizations, researchers, and policy makers. The evaluation standards then were approved by the National Council on the Handicapped for use in the evaluation. In addition to their role in the national evaluation, the standards were also designed to serve as a self-evaluation tool for the centers.

This report describes the evaluation's key findings. The study draws upon data acquired through: a mail survey of all 156 Part-B-funded centers, to which 121 centers responded; on-site interviews with center staff, consumers, and community agency representatives at 40 sample sites; a mail survey of 2,700 consumers selected from 36 sample centers, to which 1,030 consumers responded; and a mail survey of 180 local community agencies, to which 100 agencies responded. Findings presented are based on analysis of survey respondents.

Study findings primarily reflect data from the 1984-85 project year, during which the 156 centers received Part B funds totaling $21 million, at a average award of $134,600. The average Part B funding for the 121 responding centers was $133,900 with a median of $130,000. Overall, the centers can be described as consumer-oriented organizations, focusing on community changes as well as individual client services. Their primary goals are to increase independent living options for individuals with disabilities, and to promote the maximum integration and participation of this population in society.

State vocational rehabilitation (VR) agencies act as the Part B grantee for 79% of the 121 centers responding to the survey, generally subcontracting to local community organizations to provide services (69%), although a few VR agencies operate independent living programs themselves (10% of the centers are located within VR agencies). The remaining 21% of the centers (25 centers) received funds directly from the federal government.[1]

SUMMARY OF FINDINGS RELATED TO SECTION 711(c)(3) REQUIREMENTS

"(A) the number and types of handicapped individuals assisted" and "(B) the extent to which individuals with varying handicapping conditions were served"

The 121 centers responding to the survey (78% of all Part B centers) reported serving more than 48,000 persons with disabilities during 1984-85, as well as 14,000 nondisabled individuals (family and friends). These centers reported that nearly 56,000 additional individuals received information and referral assistance.[2]

The Title VII Part B centers provided services to a population with a wide range of disabilities. As estimated, 75% of the 990 consumers responding to the survey were severely disabled (as defined by receipt of SSI, total blindness, or use of attendant care).[3] Individuals with orthopedic disabilities were the largest group served (24,000 or about 48%); followed by persons with hearing impairments (8,100 or about 17%); "other" disabilities (7,400 or about 15%), including diabetes, epilepsy, stroke, and head injuries; and visual impairments (5,700 or about 12%). Mental illness and mental retardation were the categories least frequently reported, together comprising only 8% of the consumer population (about 3,900). Two-thirds of the 121 centers served at least five of the six major disability groups, allocated to direct client services.[6] The cost per consumer receiving direct services averaged $435 annually, of which $191 was provided by Part B.

"(F) how services provided contribute to the maintenance of or the increased independence of handicapped individuals assisted"

Unlike vocational rehabilitation programs with a focus on employment outcomes, the independent living centers do not have a single goal or measure of success. Rather, they respond to a wide range of particular needs and goals expressed by their consumers, ranging from housing and attendant care to enhanced self-direction and personal growth. Thus, the assessment of program effectiveness must include a wide range of measures.

The 121 responding centers reported that their efforts contributed to raising more than $7.5 million in additional funding for attendant care, adding over 3,000 qualified attendants to local attendant pools, and helping 5,000 individuals secure attendants; making more than 1,800 housing units accessible, and helping 2,250 people improve their housing accessibility; developing over 1,000 jobs, and helping 1,150 individuals secure jobs; making over 2,300 ramps and curb cuts, and helping 2,000 people move to less restrictive environments.[7] These types of community changes are directly related to disabled individuals achieving equal access to society as well as their ability to either achieve or maintain an independent lifestyle.

The responding centers reported a total of 58,000 positive individual consumer outcomes achieved.[8] Consumers' self-reports of outcomes were even higher.[9] Over three-fourths of the 990 consumer respondents achieved at least one improvement in housing, income, transportation, education, or employment situation. Almost 90% (880 consumers) reported an outcome in at least one of the following areas: personal/social change; acquiring adaptive aids, benefits, and/or services; developing skills; and acquiring knowledge associated with living more independently. Over 90% (n=906) reported either a situational improvement or some other type of gain.

while only 11% (13 centers) reportedly served a single disability group. These latter centers were funded specifically to serve individuals with visual impairments.

"(C) the types of services provided"

The Title VII Part B centers provided a wide range of independent living support services.[4] Almost all of the 121 responding centers provided the services specified in the evaluation standards -- advocacy, independent living skills training, peer counseling, and information and referral. Most centers offered a wide range of other types of assistance to facilitate consumer goal achievement, including services related to housing, attendant/homemaker assistance, transportation, equipment, and social/recreational activities. A majority of the centers also provided other types of non-peer counseling, and communication assistance such as interpreter and reader services. Finally, over one-third of the centers provided vocational, educational, and family support services.

"(D) sources of funding" and "(E) the percentage of resources committed to each type of service"

The responding centers' total annual budgets (N=111) ranged from $43,000 to $1.3 million, with a median of $240,000 and an average of $323,000, of which the Part B share was about 44%.[5] The second largest source of funds was state monies, received by 67 (57%) of the centers and comprising approximately 24% of the centers' total program funding. Almost half (58) of the centers received funding from private sources, which comprised about 8% of overall center budgets. Other federal funds and local funds accounted for a very small portion of the centers' budgets (each less than 6%). The longer centers were in operation, the less heavily they tended to rely on Part B funds.

Centers devoted an average of one-fourth of their resources to community change and capacity-building activities, with the remaining three-fourths

Statistical analyses showed that positive outcomes were more consistently associated with the types and amount of services received than with center organizational factors or individual consumer characteristics, and that center services had contributed substantially to consumer gains in independent living.[10] Moreover, about half (n=467) of the consumer survey respondents directly attributed the improvements they had achieved to help they received from a center.[11]

"(G) extent to which handicapped individuals participate in the management and decision-making in the center"

A majority of the 121 responding centers had a disabled director, 55% (66 centers) had Boards with a majority of disabled members, and on average 51% of center staff had disabilities.[12] The community agencies surveyed confirmed that involvement of disabled individuals in center policy direction and management was emphasized by most centers.

Thirty-two percent (318) of the consumers surveyed reported some kind of involvement in center operations, including serving on a Board of Directors or an advisory committee, working as paid or volunteer staff, or evaluating services. Consumers rated the centers as highly effective in involving disabled individuals in running the center.

However, among the centers there were a substantial number that exhibited less participation of individuals with disabilities. In almost 30% of the 121 responding centers, less than a fifth of the board members had disabilities. Most of these centers operated within an umbrella organization. While disabled individuals in these centers frequently were involved in staff roles, they were much less likely to be involved in policy direction and management roles.

"(H) the extent of capacity-building activities including collaboration with other agencies and organizations" and "(I) the extent of catalytic activities to promote community awareness, involvement, and assistance"

Study findings indicated that the 121 responding centers were involved extensively in capacity-building activities, including collaboration with a wide range of other community and public organizations[13]. A majority of the centers reported that they had provided information to other agencies working with persons with disabilities. Nearly two-thirds of the 100 responding community agencies reported receiving information and technical assistance from centers; 75% of these agencies referred consumers to centers, and over half had cooperated with centers in service provision and advocacy.

The centers' reports of their community development efforts were confirmed by the community agency responses, which indicated that centers had substantially expanded personal care and transportation options, and had promoted disability awareness in the community. Over half (55) of the community agencies also reported that contact with a center led to an increase in their own efforts to improve community options for persons with disabilities.

Finally, almost three-fourths of the 100 responding community agencies rated the centers as very good or outstanding advocates in their communities. Centers that allocated more resources to community efforts and that involved more consumers in the management and operation of the center were more likely to have greater community impacts.

"(J) extent of outreach efforts and the impact of such efforts"

For centers serving rural areas, outreach often involves staff efforts to reach consumers' homes in order to bridge the distances and physical access barriers associated with rural living for people with disabilities. For urban areas, outreach more often refers to publicity efforts and cultivating contacts with private and public community agencies and professionals to ensure their referral of disabled individuals to the center. The results of center outreach efforts were reflected in the consumer survey responses -- 62% of the 945 consumers responding reported they had learned about the center from other agencies, 15% had heard of the center directly from center staff and publicity, and 23% learned by word of mouth from other consumers.[14] While the impact of outreach is difficult to assess, the disability distribution of consumers served by centers is similar to that of the nation as a whole.[15]

OTHER MAJOR FINDINGS

Center Management Practices

Centers within umbrella agencies tended to have more sophisticated management practices, and generally had adopted the procedures of the parent agency, or simply had the umbrella administration conduct certain activities for them.[16] While most of the 121 responding centers collected data appropriate for assessing performance, the data were not always readily retrievable or comparable because of the lack of standardized service definitions and outcome measures. This was particularly true among smaller centers with limited resources, centers that were not required to report such data on an ongoing basis to funding agencies, and those whose records had not been computerized.

Factors Contributing to Success

Analyses were conducted of the effect of service, organizational, and consumer characteristics on consumer outcomes.[17] The most significant factors influencing consumers' success were the service characteristics. These included the types of services received, the overall amount of service, the consumer's personal and continued contact with the center over time, the use of central case managers, and the provision of peer role models to consumers via contact with disabled staff, and all contributed to consumer outcomes, regardless of the consumer's characteristics. The centers that reported higher outcomes were those with higher percentages of staff with disabilities, higher percentages of funding from nonfederal sources, and those that received their funding directly from the federal government. The consumers who reported higher outcomes tended to be younger, had disabilities other than mental retardation, were (or had previously been) VR clients, and lived in supervised settings.

Conclusion

The Title VII Part B Centers for Independent Living Program is successfully helping large numbers of disabled citizens maintain or improve their ability to live independently in their communities. They accomplish this through individual and direct services, referral to other resources, and activities targeted towards community change. There remains much diversity among centers in targeted client populations, services offered, management practices and systems in place, and involvement of individuals with disabilities in center planning and management. Some of this diversity is an appropriate response to variation in local needs. However, it also appears that many centers would benefit from increased guidance and technical assistance, greater information exchange with other centers, and increased levels or stability of funding. Also, the centers collect a wealth of information about their services and the consumers they serve that could be more valuable to program planners and policy makers if definitions and measures were uniform across centers.

FOOTNOTES

[1] For this section, see Chapter II, esp. pp. 19-21.

[2] See Chapter III, pp. 25-26.

[3] See Chapter III, esp. pp. 26-28 and Appendix D, pp. D-17 - D-19.

[4] See Chapter IV, esp. pp. 36-39 and Appendix D, pp. D-49 - D-53.

[5] See Chapter II, esp. pp. 19-22.

[6] See Chapter II, esp. pp. 22-23.

[7] See Chapter V, esp. pp. 56-58 and Appendix D, pp. D-29 - D-43.

[8] *Ibid*.

[9] See Chapter V, esp. pp. 58-67 and Appendix D, pp. D-29 - D-43.

[10] See Chapter V, pp. 67-74; Chapter X, pp. 110-117; and Appendix D, pp. D-63 - D-66.

[11] See Chapter V, pp. 58-59, 64.

[12] See Chapter VI, pp. 77-83 and Appendix D, pp. D-63 - D-66.

[13] See Chapter VII, pp. 85-96.

[14] See Chapter VII, pp. 90-93.

[15] See Appendix D, pp. D-11 - D-13.

[16] See Chapter VIII, pp. 101-107.

[17] See Chapter IX, pp. 109-129; Chapter V, pp. 67-74; Chapter VII, pp. 99-98.

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I. INTRODUCTION

The evaluation of Title VII Part B, of the Rehabilitation Act as Amended, Centers for Independent Living Program described in this report is the first such large national effort to describe and evaluate the effectiveness of independent living centers. The Centers for Independent Living Program is a small discretionary grant program, administered by the Rehabilitation Services Administration, that provides support for a range of independent living services with the goal of meeting the needs of individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from services which enhance their ability to live and function independently in the community.

In 1978, Title VII Part B of the Rehabilitation Act of 1973 was amended to establish a grant program for independent living centers. In 1979, funding for the first ten centers was allocated. The Title VII Part B program currently provides $21 million in grant funding to 156 agencies and community-based organizations around the country. These funds support a variety of individualized services and community activities designed to maximize independent living options for disabled individuals. The independent living centers respond to a variety of needs expressed by disabled individuals, by rehabilitation professionals, as well as by a general societal commitment to improving the quality of life for people with disabilities and maximizing integration into the mainstream of society. They are based on the belief that a range of services not provided by existing programs could prevent institutionalization and, just as importantly, facilitate full participation in the local community. To achieve these goals, centers offer assistance in areas such as learning to use public and private transportation, general household and financial management, job-seeking, and obtaining needed public assistance.

This report presents the findings of a comprehensive evaluation of these centers that was undertaken to: (1) provide information requested by Congress about the operations and effectiveness of the national program; (2) explore the factors contributing to the success of the program; (3) contribute to a better understanding of how independent living centers function; and (4) assist the federal government, the state grantees and the centers themselves to better manage the program. The remainder of this Chapter describes the 1984 evaluation provisions and study purposes developed in response to these provisions; the methods used to conduct the study; and the organization of this report.

PURPOSES OF THE STUDY

As public funding for independent living centers has increased, increasing demands for accountability have been placed on the centers. The current directive (PL 95-602, Sec. 711) mandating the program by Congress Section 711(c) of the Act, stipulates that applications for funding shall:

- "provide assurances that handicapped individuals will be substantially involved in policy direction and management of such center, and will be employed by such center"; and
- "contain assurances that the independent living center to be assisted by such grants shall offer handicapped individuals a combination of independent living services, including..." 14 different specified services with the last service being a general category specifying ..."such other services as may be necessary and not inconsistent with provisions of this title."

That same legislation specified that the Secretary of the Department of Education would "develop and publish standards for evaluation consistent with..." the provisions of the legislation, and directed the Secretary to submit a report based on a "comprehensive evaluation" of the centers, to include "recommendations for the improvement and continuation" of grantees and the support of new centers. The evaluation standards were to be "consistent with" the overall "standards" previously specified by Congress and were to be developed by obtaining and considering the recommendations for such standards "from national organizations representing handicapped individuals and independent living programs; and from independent living centers, professionals serving handicapped individuals, and individuals, associations, and organizations engaged in research in independent living." The evaluation standards were further to be reviewed and approved by the National Council on the Handicapped for use in the evaluation.

In response to these provisions, this study was designed to address two broad purposes: (1) development of independent living evaluation criteria for use in the national study and for use by independent living centers in their self-evaluation of operations and performance; and (2) conduct of a comprehensive national evaluation of the Centers for Independent Living Program based on these criteria. The first of these purposes was addressed during the early months of the study during which evaluation criteria were developed to address the study questions raised by Congress in the amendments. These were reviewed with the study's Advisory Committee and over 500 respondents, revised, and subsequently approved as evaluation standards by the National Council on the Handicapped in January 1985. The evaluation standards are listed in Figure I-1, and a description of their development is included in Appendix A.

The second study purpose was addressed by the development of a study design and analysis plan based on the evaluation standards, the

Figure I-1

Independent Living Evaluation Standards

PHILOSOPHY

Standard No. 1: The Center shall promote and practice the Independent Living Philosophy:

TARGET POPULATION

Standard No. 2: The Center shall have a clearly defined target population that includes a range of disabilities.

OUTCOMES AND IMPACTS

Standard No. 3: The Center shall increase individual consumer achievement of Independent Living goals.

Standard No. 4: The Center shall increase the availability and improve the quality of community options for Independent Living.

SERVICES

Standard No. 5: The Center shall provide to disabled individuals within the Center's target population and/or their families Independent Living Services.

Standard No. 6: The Center shall provide Information and Referral to all inquirers including those from outside the Center's target population.

Standard No. 7: The Center shall conduct activities to increase community capacity to meet the needs of individuals with disabilities.

ORGANIZATIONAL MANAGEMENT AND ADMINISTRATION

Standard No. 8: Qualified disabled individuals shall be substantially involved in the policy direction, decision-making, service delivery, and management of the Center.

Standard No. 9: The Center shall establish clear priorities through annual and three-year program and financial planning objectives.

Standard No. 10: The Center shall use sound organizational and personnel management practices.

Standard No. 11: The Center shall practice sound fiscal management.

EVALUATION

Standard No. 12: The Grantee and the Centers shall conduct annual self-evaluations and shall maintain records adequate to measure performance on these Independent Living Center Evaluation Standards.

collection of quantitative and qualitative data, and the analysis of those data as prescribed in the design. The study was intended to provide information that would assist program planners and policy makers, as well as the centers themselves.

OVERVIEW OF THE STUDY DESIGN

The two major activities mandated by Congress for this evaluation -- development of evaluation standards for use by independent living programs and conduct of a comprehensive evaluation of the program's overall achievements -- were intended to generate information on 11 areas of interest to Congress about the center program:

(a) the numbers and types of handicapped individuals assisted;

(b) the extent to which individuals with varying handicapping conditions were served;

(c) types of services provided;

(d) sources of funding;

(e) the percentage of resources committed to each type of service;

(f) how services contributed to the maintenance or the increased independence of handicapped individuals assisted;

(g) the extent to which handicapped individuals participate in the management and decision-making in centers;

(h) the extent of capacity-building activities, including collaboration with other agencies and organizations;

(i) the extent of catalytic activities to promote community awareness, involvement, and assistance;

(j) the extent of outreach efforts and the impact of such efforts; and

(k) the comparison, when appropriate, of prior year(s) activities with most recent year activities.

In response to the mandate's specifications, the independent living center evaluation standards developed at the outset of the evaluation address these 11 areas of Congressional interest. The 12 standards are organized into six major areas: (1) philosophy, (2) target population, (3) outcomes and impacts, (4) services, (5) organizational management and administration, and (6) evaluation. The specific relationships among the areas of Congressional interest, independent living center evaluation standards, and issues addressed by the comprehensive evaluation are described in Table I-1. As the table shows, although the evaluation standards and data elements build upon Congressional questions and concerns, they go further to specify to grantees and centers a broad range of criteria identified as essential to evaluating performance. The specific data elements operationalize the Congressional questions, enabling centers to measure their achievement of each standard. Table I-1 illustrates the complexity of the evaluation and the broad range of activities and outcomes it measured. Unlike most rehabilitation programs with their clear employment focus, there is no single desired outcome for independent living centers. Since the centers address a broad array of individual needs, a variety of different outcome measures are needed. Since they address the special needs of their local communities, centers are extremely varied in their characteristics.

These issues present a unique challenge for conducting a comprehensive program evaluation. Figure I-2 presents a conceptual model of the evaluation approach. The analysis builds on this conceptual model in two ways: (1) the data are summarized to provide a description of each of the different types of inputs, processes, and outcomes; and (2)

Table I-1

Relationship Between Independent Living Center Evaluation Standards and Legislative Requirements

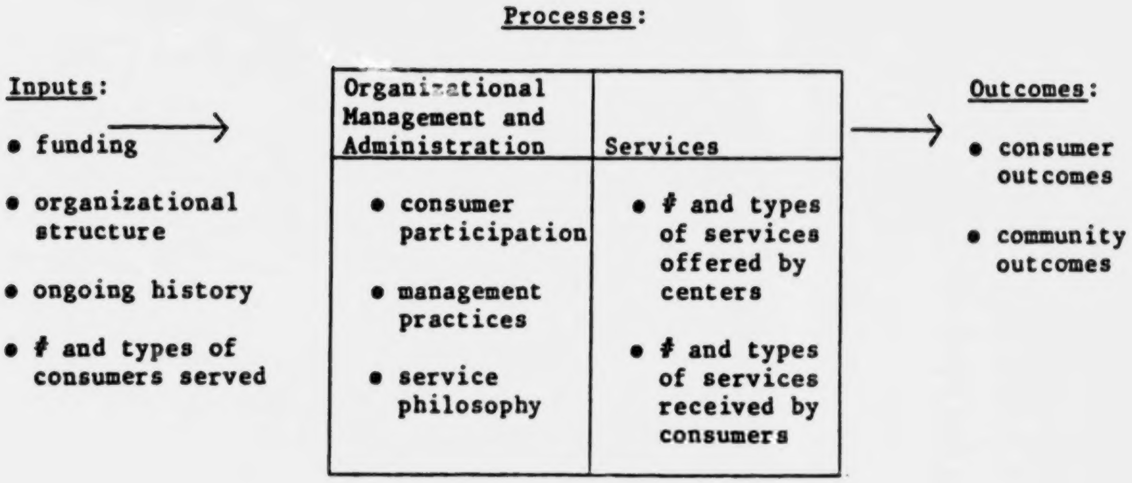
Section 711 (c)(3) Requirement	Standard	Data Element
(A) The number and types of handicapped individuals assisted (B) The extent to which individuals with varying handicapping conditions were served	1, 2, 9, 12 (addressed in Chapter III of this report)	1.5, 1.8 -- Promote equal access to society, range of services to all people with disabilities
		2 -- Clearly defined target population including range of disabilities
		9.3 -- Specific objectives for numbers and disabilities of individuals to be served
		12.1 — Document number and types of individuals served
(C) The types of services provided	1, 5, 6, 9, 12 (addressed in Chapter IV of this report)	1.2, 1.3, 1.6 — Promote consumer control of own service objectives, self-help/self-advocacy, peer relationships and role models
		5.1 - 5.14 -- Provide advocacy, ILS training, peer counseling; may provide legal, other counseling, housing, equipment, transportation, social/recreational, educational, vocational, communication, attendant/homemaker, electronic services
		6 -- Provide information and referral
		9.4, 9.5 -- Annual and three year planning for service priorities, types of services, service delivery procedures
		12.2 — Document types and units of service
(D) The sources of funding (E) The percentage of resources committed to each type of service provided	11, 12 (addressed in Chapter II of this report)	11.1, 11.5 — Annual budget that identifies funding sources and allocation across services, determination of costs of services and activities
		12.6 — Maintain financial records
(F) How services provided contributed to the maintenance or the increased independence of handicapped individuals assisted	3, 12 (addressed in Chapter V of this report)	3.1 - 3.20 — Increase consumer goal achievement in housing, living arrangements, finances, transportation, personal care, nutrition, household management, mobility, health, assistance devices, education, employment, community involvement, family life, recreation, personal growth, social skills, communication skills, self direction, consumer and legal rights
		12.3 — Document individual outcomes

Table I-1 (continued)

Section 711 (c)(3) Requirement	Standard	Data Element
(G) The extent to which handicapped individuals participate in management and decision-making in the center	1, 8, 10, 12 (addressed in Chapter VI of this report)	1.1 — Promote consumer control of policy direction and management 8.1 - 8.3 — Involve disabled in policy direction, decision-making, service delivery, management; disabled given preference as board members (minimum 51%), managers and staff 10.1 - 10.6 — Specify roles of Board and staff; job descriptions; clear lines of authority; personnel reference appraisal, equal opportunity and affirmative action; staff and Board training 12.7 — Consumer evaluation of program
(H) The extent of capacity-building activities including collaboration with other agencies and organizations (I) The extent of catalytic activities to promote community awareness, involvement and assistance (J) The extent of outreach efforts and the impact of such efforts	1, 4, 6, 7, 11, 12 (addressed in Chapter VII of this report)	1.4, 1.7 — Promote equal access to society, address specific needs of local community 4.1 - 4.12 — Increase community options in housing, transportation, personal care, education, employment, communication, reduced barriers, disability awareness, consumer involvement in community, health care, legal services 6 — Provide information and referral 7.1 - 7.4 — Provide advocacy and TA, public information, outreach; establish role in disabled community 11.4 — Resource development activities 12.4 — Document community impacts
(K) A comparison, when appropriate, of prior year(s) activities with most recent year activities	9, 11, 12 (addressed in Chapter VIII of this report)	9.1 - 9.6 — Annual and three-year planning for goals, work plan, specific objectives, service priorities, service delivery procedures, and budget projections 11.1, 11.2, 11.3, 11.5 — Annual budget, budget monitoring system, annual audit, determination of costs of services and activities 12.1 - 12.7 — Document number and types of individuals; types and units of services; outcomes; client records; financial, legal, administrative and personnel records; consumer evaluation of program.

Figure I-2

A Conceptual Model of Independent Living Services



Processes:

Inputs:
- funding
- organizational structure
- ongoing history
- # and types of consumers served

Organizational Management and Administration	Services
• consumer participation • management practices • service philosophy	• # and types of services offered by centers • # and types of services received by consumers

Outcomes:
- consumer outcomes
- community outcomes

multivariate analysis is used to explore the extent to which outcomes are influenced by service, organizational, and consumer variables. Through this approach, all of the Congressional questions and evaluation standards are addressed.[1] Table I-1 also indicates the specific chapter of this report in which each set of issues has been addressed.

OVERVIEW OF STUDY METHODS

The findings of the comprehensive evaluation are based on analysis of data collected through:

(a) a mail survey of 156 center grantees for the most recent project year;

(b) interviews with center project directors and staff, and observations of projects in 40 centers selected on a random basis;

(c) a mail survey of 2,700 past and current disabled consumers of center services, selected on a random basis from 36 of the centers visited; and

(d) a mail survey of 180 community agencies in the communities served by the 36 sample centers.

These data collection instruments are included in Appendix B. Data collection occurred in the summer and fall of 1985. Table I-2 presents the response rate for each of the evaluation's data collection efforts. A detailed discussion of the study design and methods is presented in Appendix C, including an analysis of nonresponse patterns.

The analysis of the nonrespondent consumers indicated that the reasons for nonresponse were principally that the consumer had misplaced the questionnaire or neglected to respond out of disinterest. When 245 sample nonrespondent consumers were probed concerning their experience with the center, the answers indicated that nonrespondents were as positive toward the usefulness of center services as survey respondents.

Table I-2

Response Rates for Data Collection Activities

Data Collection Method	Number of Cases	Responses n	Responses %
1. Center Site Visits	40	40	100%
Center Mail Survey	156	121	78%
2. Consumer Interviews on Site	80	80	
Consumer Mail Survey	2,700	990*	37%
Nonrespondent Follow-Up	330	245	74%
3. Community Agency Interviews on Site	40	40	100%
Agency Mail Survey	180	100	56%

*Surveys continue to be received even four months after initial mailing. At the time of writing, an additional 40 responses had been received, too late for inclusion in the analysis.

An analysis of 22 nonrespondent centers indicated that they were very similar in characteristics to responding centers. (See Appendix C for a more detailed analysis of nonresponse.) Because the community agencies surveyed were sampled from lists recommended by the centers, a formal analysis of nonresponse was not conducted, especially since the response rate was quite high. The respondents did include a broad cross-section of community agencies of the kinds centers collaborate with, and no obvious biases were visible in terms of the kinds of agencies represented.

As mentioned previously, the evaluation design and analytic plan underlying the surveys was complex and extensive, probing not merely frequencies of national response to the various questions, but the multivariate impact of organizational characteristics upon services received and outcomes, and the impact of organizational characteristics, services, and consumer characteristics upon outcomes. The findings from those analyses shape and qualify the reporting of frequencies in the following report, and are the bases for a summary section on factors influencing center operations and outcomes in Chapter X. Appendix E provides a more detailed review of these analyses. The data base developed in this evaluation is the first large-scale national data base on independent living programs, their consumers, and outcomes.

In regard to the survey findings, several cautions are necessary. First, because RSA has not previously required uniform information from the projects, the comprehensiveness and accuracy of information available at the project level vary. The surveys created a common set of questions to which centers responded. The extent to which centers estimated data for the survey's categories because their own data records did not fully conform to those categories has been reported here. Second, for various questions (e.g., severity of disability), there is no common definition across projects or nationally; the bases for defining severity from the information that consumers could provide on themselves is described in the description of center consumers in Chapter III. Such definitions are not used for the center survey, precisely because of the lack of common definitions being used by the centers.

Third, many different types of analyses are drawn on in the report -- frequency counts, cross-tabulations, correlations and multivariate regressions. Patterns which one might observe from frequencies are sometimes (though rarely) negated by the more complex analyses. We have emphasized statistical significance throughout the report, showing both .05 and .20 levels, to reduce the risks of overlooking important factors, as is appropriate with a demonstration program trying out new approaches.[2]

Last, because there are so many different types of outcomes which can represent legitimate gains for consumers, it is not simple to define what constitutes a "successful" center. Most factors seem to contribute to some types of success and not others. Some centers seem to target some types of outcomes and other centers emphasize others. Almost all consumers responding to the survey reported gains, but the nature and extent of gains varied dramatically. While most rehabilitation programs simply measure success by whether an individual has obtained employment, independent living services address essentially all aspects of life from housing and employment to personal development, and thus can result in changes ranging anywhere from an ability to manage money to a complete change of living situation and lifestyle.

ORGANIZATION OF THIS REPORT

The analysis plan for this study called for the analysis of findings for each of the 12 evaluation standards. These standard-by-standard findings are presented in Appendix D. The main body of this report, however, is organized according to the original Congressional questions which combine information across two or more evaluation standards. Each chapter begins with a reference to the Congressional question(s) and evaluation standards being addressed. Occasionally the reader is referred to the standard-by-standard analysis in the appendix for more detail.

Following the presentation of findings in response to the Congressional questions is a chapter delineating some of the program management issues and policy questions raised during the conduct of the study. This is followed by a discussion of the factors influencing the operations and success of the program and brief summary conclusions. In addition to presenting detailed standard-by-standard findings (Appendix D), the appendices also provide a description of the development of the evaluation standards (Appendix A), the data collection instruments (Appendix B), a description of the study methodology (Appendix C), and a detailed discussion of the multivariate analysis (Appendix E). Descriptive statistics for services, outcomes and characteristics of a "typical" center are included in Appendix F.

FOOTNOTES

[1] The last Congressional question soliciting a comparison, when appropriate, with previous years' activities was not addressed directly since the evaluation standards are newly developed and standardized reporting has not been required. However, the evaluation standards do require data that would eventually make cross-year comparisons by project feasible in the future. Thus, this issue is addressed by assessing centers' current data collection and reporting mechanisms.

[2] The choice of an appropriate significance level for testing hypotheses involves a conscious trade-off of the costs of Type I and Type II errors. In academic research, the costs associated with the error of a "false positive," i.e., prematurely accepting a relationship which may later prove to have arisen by chance, are deemed very high as they misdirect future avenues of research; thus, the tradition of .01 and .05 significance levels have emerged, which treat the costs of "false positives" as roughly 20-100 times as great as the cost of "false negatives." In policy analyses and program evaluations, where decision-makers are trying to determine which of several courses of action or program strategies to pursue in a context of pressing social problems, the costs of "false negatives" are much greater, i.e. prematurely rejecting a relationship as arising from chance, when the relationship may later prove valid. The .20 level of significance still treats the costs of "false positives" as roughly five times more severe than the costs of "false negatives," but gives greater emphasis to avoiding "false negatives." The .20 level roughly corresponds to a t-ratio of 1.0, and in statistical modeling corresponds to that level of stability in a relationship where the inclusion of an independent variable increases the overall prediction of the dependent variable more than is lost by the reduction in degrees of freedom. Cf. Stuart S. Nagel and Marian Neef, "Determining an Optimum Level of Statistical Significance," Evaluation Studies Review Annual (Sage Publications, 1977), pp. 146-155.

II. OVERVIEW OF THE CENTERS FOR INDEPENDENT LIVING PROGRAM

HISTORY AND DEVELOPMENT OF THE CENTERS FOR INDEPENDENT LIVING

The role of the federal government in funding the independent living centers has been one of greatly enhancing and dramatically increasing the rate of development of centers across the country. The Centers for Independent Living Program funded through Title VII, Part B of the Rehabilitation Act has represented a national effort to operationalize principles and programs that actually predate the federal funding by a number of years.

In 1962, four students with severe disabilities from a disabled students program were transferred from an isolated nursing home to a modified home closer to their campus, the University of Illinois at Champaign-Urbana. These early pioneers helped make the University of Illinois architecturally accessible and created a self-help policy that became an important first step in what has come to be called the "independent living movement."

In the early 1970's, the independent living movement was given a second and more dramatic boost when several students with severe disabilities at the University of California at Berkeley created the Center for Independent Living (CIL). They incorporated in 1972 as a self-help group and were motivated by the philosophy that disabled persons were best able to determine their own needs and should manage their independent living service delivery programs themselves.

Since then, more than 300 independent living programs have emerged. Most are nonresidential and virtually all include a focus on developing the community environment to better suit the needs of persons with disabilities. Each program offers its own unique combination of community and self-help services. Programs provide services ranging from peer counseling, transportation, and self-help skills training to attendant care management and health maintenance. They also help educate the public about the needs and capabilities of individuals with severe disabilities. In addition, there is a focus on developing a sense of self-worth and ability in disabled consumers themselves, helping them to become more effective contributors in their own families and communities.

The importance of independent living support services was first acknowledged by Congress in the Rehabilitation Act of 1973 as part of a shift in program priorities towards individuals with the most severe disabilities. The Act was first vetoed by the President, in part because of concern that the inclusion of provisions for an independent living focus for some disabled clients might defuse the employment focus of the Vocational Rehabilitation program. Proponents of the program argued that independent living services would, in fact, contribute to vocational outcomes and the Act was affirmed over a presidential veto with the discretionary independent living provisions intact.

In 1978, Title VII, Part B of the Rehabilitation Act established a grant program for independent living centers. In 1979, funding for the first ten Title VII, Part B centers was allocated. New centers were added in 1980 and 1981. During the 1984-85 project year, 156 Title VII, Part B independent living centers were funded through 84 grants.

The Rehabilitation Act Amendments of 1984 extended funding for all current centers for one year and provided for a new role for the National Council on the Handicapped. Also included were the requirements for developing evaluation standards for the Title VII, Part B Program Centers for Independent Living and the conduct of the study described in this report.

The Title VII, Part B funds are distributed in the form of grants, mostly to designated state units (VR agencies). The state agencies generally select organizations within their states with whom they subcontract for the delivery of independent living services. The states have considerable leeway in selecting service-delivery organizations to carry out the Title VII, Part B provisions. These providers are not in all cases the consumer-based free-standing non-profit agencies typical of the early pioneers. Rather, in some cases, more traditional rehabilitation or social service agencies have been chosen to develop an independent living program under their auspices. As these programs mature, some evolve into free-standing agencies. In some cases, the VR agencies have elected not to participate in the program, but rather to allow local organizations to apply directly for the funds. (The Act specifies that if the designated state unit does not submit an application, RSA may receive applications from and make grants directly to local public agencies or private non-profit organizations.) Thus, the centers that make up the current Title VII, Part B program are extremely varied in their characteristics.

DESCRIPTION OF THE CURRENT PROGRAM

RSA awarded 84 grants for the 1985 fiscal year that supported activities at 156 independent living centers. Among the 121 centers responding to the center mail survey, most had been in operation for five years or more (71%) and 29% had been in operation six years or more. Sixty percent of the centers had been receiving Title VII, Part B funds for five or six years since the first two years of the program. All ten of the first centers to be funded under Title VII were still receiving funding through the program.

The remainder of this chapter describes the organizational characteristics of the centers. The services they offer and the consumers they serve are described in subsequent chapters. Appendix F includes detailed tables describing center characteristics.

Organizational Structure

For most centers (79%), the state VR agency operates as Part B grantee, subcontracting with the centers for service delivery. The remaining 21% receive their funds directly from RSA. Only seven percent of the centers responding to the survey are operated directly or indirectly by state VR agencies. (Of the nine programs operated by VR, two identified themselves as direct grantees and the other seven are receiving funds through VR.) Most of these subcontractors are free-standing organizations (62%), with the remaining programs operating within umbrella organizations. Some centers were established by an umbrella agency and then became independent later. Thus, those centers which operate as free-standing organizations tend to have been in operation longer (6.8 years on average) than those in umbrella agencies (4.7 years). Also, their annual budgets tend to be larger (an average of $436,000 compared to $180,000), and they tend to be less dependent on Part B funding (an average of 43% of overall budget compared to 75%).

Of the 38% of the centers within umbrella agencies, 73% are under non-profit umbrellas and 27% are within government agencies. Thus, overall, 90% of the centers are non-profit organizations and 10% are government agencies (of which three-fourths are state VR agencies).

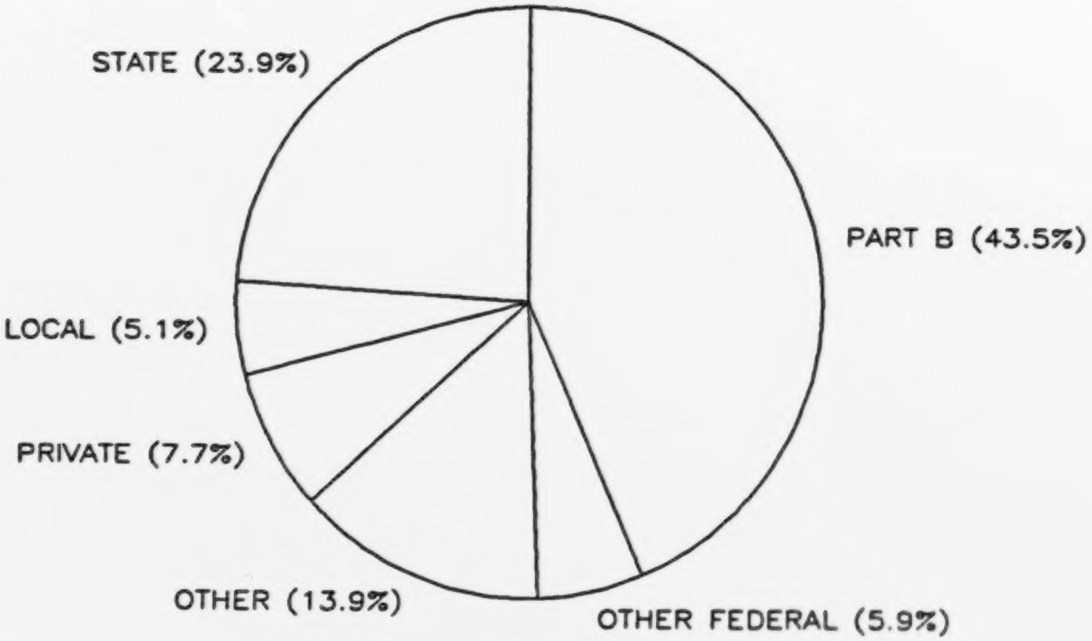
Sources of Funding

As shown in Figure II-1, the Part-B-funded centers overall received about 44% of their funding from Title VII, Part B grants, with over half of their funding coming from other sources. The total federal share of costs, including other federal sources, was almost half the total budgets of these centers. The state share comprised about 24%, with local governments contributing 5% and private sources contributing almost 8%. It is important to note that Title VII, Part B grants provide funding to about half of the independent living centers

Figure II-1

Sources of Funding for the Part B

Centers for Independent Living



operating nationwide. Those programs not receiving Part B funds during 1984-85 were not included in this study, but other sources suggest they may be similar in terms of range of funding levels. If this were the case, then Part B funds would account for about one-fourth of the total costs of independent living programs nationwide.

The median budget of respondent centers was $240,000 (mean = $323,182) and ranged from $43,000 to $1.3 million. About a third of the centers had budgets under $175,000 a year, while another third operated on over $300,000 a year. Less than half (44%) of all centers received more than two-thirds of their annual funding from Part B, while over one-fourth (28%) have less than 33% funding from Part B. This distribution may indicate that most centers address priorities and objectives other than or in addition to those set by the federal government.

Part B funding grants per center ranged from $1,500 to $400,000 and from 6% of center funding to 100%, with the median grant being $130,216 and the median percent of funding from Part B being 58%. The smaller the center, the higher the proportion of funding that came from Part B.

Use of Part B Funds

The extent to which Part B funds various activities or components of a center's budget varies dramatically. Among respondent centers, 24% reportedly use their Part B funding for specific disability groups, and 39% for specific staff. Most centers merge Part B with other funds in their internal accounting of expenditures; thus, 68% of centers report that their Part B funding is used across all center activities, while 32% reported using the funds for specific services. When Part B funds are specifically targeted, the services supported most often are independent living skills training, counseling, and administrative services. Advocacy and information and referral services are also frequently supported by Part B monies.

Among centers using Part B funds for specific disability groups, most often funds are targeted to serving individuals who are blind or visually impaired. Some centers also target Part B funds to other groups such as individuals who are mentally retarded, mentally ill, or brain-injured or to those who are deaf or hearing-impaired. A few centers reserve funds to serve people with multiple disabilities.

Among the centers that use Part B funds to support specific staff positions rather than merging those funds into the center's general budget, a fourth of the staff positions supported are administrators, a fourth are support staff positions, and half are direct service positions.

In summary, the Part B funds vary dramatically from center to center in their importance, and in how they are used. The more years the center had been in operation and the larger the overall budget, the more that Part B funds are used to fund specific services. The fewer the years in operation, the higher the proportion of a center's budget Part B is likely to constitute.

Cost Per Consumer Served

The average cost of direct services across the total program was \$435 per consumer served (median = \$353) over the last year, of which 44% (or \$191 per consumer) was provided by Part B funding. The range among the centers was quite large, however, extending from an annual cost of \$37 to \$5,000 per consumer served. Centers with the highest cost per consumer receiving direct services tended to be those (1) devoting more of their efforts towards information and referral activities, (2) those in operation fewer years, (3) those with larger annual budgets, and (4) those centers serving exclusively rural areas (see Table IX-3).

Staffing Patterns

During 1984-85, a total of 1,564 individuals were working during 1984-85 in the 121 centers responding to the mail survey. On average, each center had 13 staff positions. Of the total staff for the centers, 18% filled administrative positions (an average of 2.4 per center), 45% provided direct services (an average of 5.9 per center), 20% filled support staff roles (an average of 2.6 per center), and 17% held other types of positions. In addition, the centers reported the participation of 1,675 volunteers in their programs, or an average of 14 volunteers per center.

Geographic Service Area

Independent living centers funded by Part B are located in all of the 50 states, the District of Columbia, as well as in Puerto Rico, the Virgin Islands, and American Samoa. Some 20% of centers are set up to serve their entire state, rather than being responsible solely for metropolitan, rural, or suburban areas. Of all respondent centers, 24% serve exclusively rural areas, 46% serve urban (central city) areas, 10% suburban areas, and 20% mixed areas (principally statewide centers including rural, urban and/or suburban areas).

III. CHARACTERISTICS OF CENTER CONSUMERS

In response to two of the evaluation issues outlined by Congress in Section 711(c)(3) of the Rehabilitation Act, this chapter describes the characteristics of the consumers served by the Title VII, Part B independent living centers. Specifically, Congress has required information about: "(A) the number and types of handicapped individuals assisted"; and "(B) the extent to which individuals with varying handicapping conditions were served."

The evaluation standards, developed for this study using the basic framework provided by the Congressional questions, include three standards that address these issues in more detail: Standard 2 (Target Population) states that centers should have a "clearly defined target population that includes a range of disabilities," Standard 9 (Planning) includes a criterion that centers set "specific objectives for numbers and disabilities of individuals to be served," and Standard 12 (Evaluation) states that centers should "maintain documentation of the number and types of individuals served."

The following discussion is based primarily on data gathered through mail surveys of centers and consumers. The consumer population is described in terms of the numbers of individuals served by the centers, the types and severity of their disabilities, and other selected demographic characteristics.

NUMBERS OF CONSUMERS SERVED

The 121 Part-B-funded centers that responded to the Center Mail Survey reported providing services to approximately 48,100 consumers over a one-year period, and to an additional 13,800 individuals who were not disabled (e.g., family, friends). Centers varied dramatically in the number of consumers served (ranging from 28 to 8,000), depending on their budget size and other factors, but on average provide direct services to 400 disabled individuals annually (with the median center serving 219).

The centers surveyed also reported an additional 56,000 individuals to whom they had provided informational and referral assistance. Many centers did not collect demographic data on these individuals and many do not consider them to be "consumers." Thus, while information and referral is an important component of the centers' service package (and, is, in fact, identified as a primary service in the evaluation standards), individuals who received only information and referral assistance are not included in the population described here.

TYPES AND SEVERITY OF DISABILITIES

As illustrated in Figure III-1, Part B centers provided services to a cross-disability population, with orthopedically disabled impairments being the largest group served (48%). The second largest group was deaf hearing impaired (17%), followed by "other disabilities" (15%) which included diabetes, epilepsy, stroke and head injuries, and by visual impairments (12%). Mental illness and mental retardation were the smallest groups reported, together comprising 8% of the consumer population.

Slightly less than half of the centers served consumers from each of the six major disability groups, and 88% served more than one disability group. Only 11% of the centers limit their services to consumers in one major disability category. (See Standard 2 in Appendix D for more detail on these findings.)

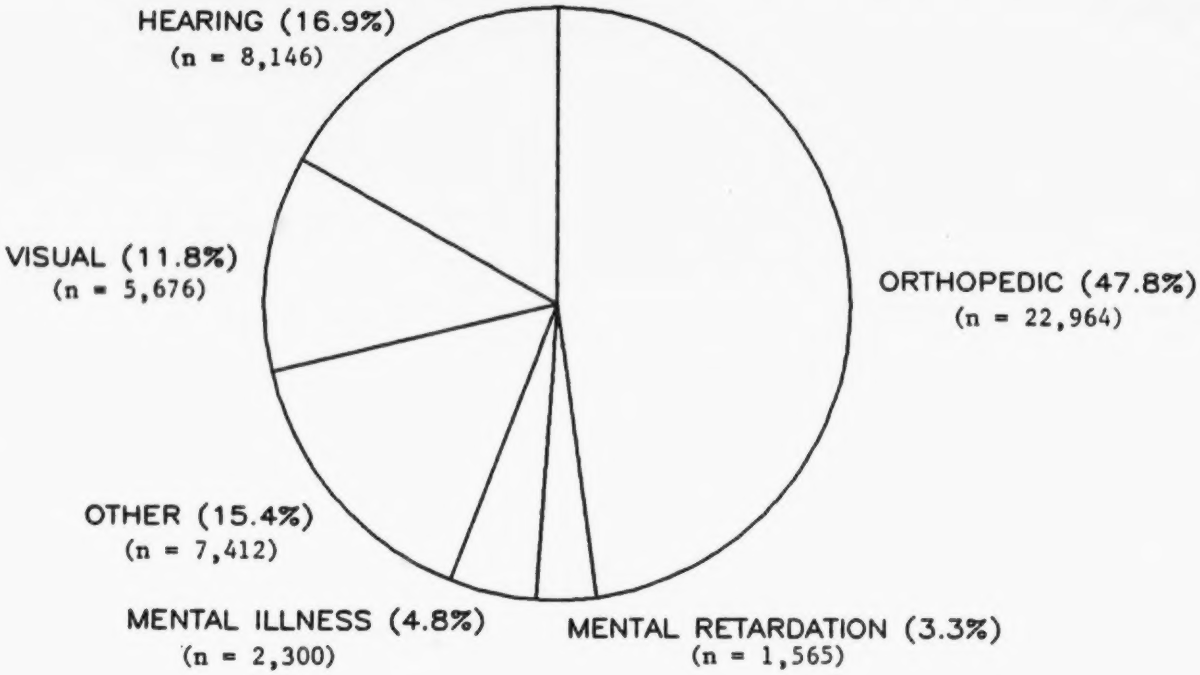
A large majority (58%) of center consumers became disabled before the age of 22. There is an equal distribution (29%) between those disabled since birth and those who became disabled as children, adolescents, or young adults.

Figure III-1

Primary Disabilities of

Independent Living Center Consumers

N = 48,063



Because centers have never been required to maintain records that identify consumers by the severity of their disability, it is difficult to determine the proportion of consumers who have severe disabilities. Data from the consumer survey, however, provide several indicators that can be used to estimate the number of severely disabled consumers. First, 57% of consumers receive either SSI or SSDI, receipt of which indicates the presence of a severe disability that limits the ability to work. An additional proxy was constructed by totaling the number of individuals who responded positively to at least one of the following: major disability of blindness, use of an electric or manual wheelchair, use of a seeing eye dog or white cane, or use of an attendant. According to these indicators, 75% of consumers have severe disabilities.

DEMOGRAPHIC CHARACTERISTICS

The consumer mail survey provided demographic detail about consumers from the 36 sample centers. This section discusses findings relating to age, gender, ethnicity, educational attainment, income levels and sources, vocational rehabilitation client status, and living arrangements.

Independent living center consumers were distributed almost equally among males and females, with females slightly predominating (54%). Table III-1 presents the age distribution of center consumers. The median age of consumers was 38, and 80% were between the ages of 21 and 60. However, centers also served a sizable portion of adults over the age of 61 (14%).

Table III-1

Distribution of Center Consumers by Age

Age	#	%
Under 21	54	5.5%
21-40	504	51.5
41-60	281	28.7
61 and Over	140	14.3
TOTAL	979	100.0%

Ethnicity

As Table III-2 shows, over three-quarters of center consumers are White, and the remaining racial and ethnic groups each are represented by less than 8% of the respondents. Table III-2 also includes a distribution of ethnic groups in the general U.S. population which illustrates that each minority group is under-represented among this sample of center consumers except for those in the Native American category. Several sample centers were located in areas with a high concentration of Native Americans. Blacks appear to be the minority group most underserved by independent living centers.

Educational Attainment

Slightly over one-third (34%) of consumers have not completed high school, and one-fifth (19%) have no formal training beyond the ninth grade (see Table III-3). However, over one-third (34%) of center consumers have received at least some college-level education.

Table III-2

Distribution of Center Consumers by Ethnicity Compared to the General Population

Race/Ethnicity	Consumer Survey Respondents		% of General Population (1980)[1]
	#	%	
White	768	78.4%	83.1
Black	69	7.0	11.7
Hispanic	56	5.7	6.4
Asian	9	.9	1.4
Native American	55	5.6	.6
Other	22	2.2	3.1
TOTAL	979	100.0%	106.3

[1] Source is U.S. Census, 1980. Total is greater than 100% since Hispanic people may be of any race.

Table III-3

Educational Attainment of Center Consumers*

Education Level	#	%
Less than Ninth Grade	85	19.0%
Some High School	67	15.0
High School Completion	135	30.2
Some College	103	23.0
College Degree	28	6.3
Some Graduate Work	22	4.9
TOTAL	447	100.0%

*At time of first contact with independent living center. Total N is smaller than for most data items because the question was asked of only those who reported a change in educational level since frst contact with the center.

Income Levels and Sources

Table III-4 shows that nearly four out of five consumers (79%) have an annual income of less than $7,200 and that over half (58%) report receiving less than $4,800 per year.

Table III-4

Income Levels of Center Consumers*

Monthly Income	#	%
Less than $199	96	22.2%
$200 to $399	155	35.8
$400 to $599	92	21.2
$600 to $799	29	6.7
$800 to $999	25	5.8
$1,000 to $1,999	25	5.8
Over $2,000/month	11	2.5
TOTAL	433	100.0%

*At time of first contact with independent living center. Total N is smaller than for most data items because the question was asked only of those who reported a change in income level since first contact with the center.

As mentioned earlier, 57% of consumers reported that their income source is Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI). Nearly one-fifth (19%) of consumers receive some income from earnings (for more detail see Standard 2 in Appendix D).

Vocational Rehabilitation Client Status

Over two-thirds (70%) of consumers are now or have been in the past VR clients, and nearly one-third (30%) currently have an open case file with VR. Many of these consumers use independent living centers as a complement to the VR services, and many became VR clients through referral by a center.

Living Arrangements

Table III-5 *displays findings related to consumer living* arrangements.

Table III-5

Living Arrangements of Center Consumers*

Living Arrangement	#	%
Institution/Primary Care Facility	107	13.2%
Parent's Home	236	29.1
Supervised or Transitional Residence	23	4.2
Cooperative or Shared Residence	30	3.7
In Own Home or Apartment	374	46.1
Other	30	3.7
TOTAL	811	100.0%

*At time of first contact with independent living center.

Although 94% of consumers are over the age of 21, only 46% live in their own home or apartment. The institutionalized population, though a small proportion of consumers served by centers (13%), is still a sizeable group, indicating that at least some centers are targeting this group for services.

SUMMARY

Independent living centers responding to the survey provided direct services to more than 48,000 disabled individuals this year. While it is difficult to describe a typical center consumer, that person is likely to be white, orthopedically and severely disabled, about 40 years old, and nearly as likely to be male as female. The average consumer probably has not participated in post-secondary education and survives on a very low income, more likely than not from SSI or SSDI. Finally, the consumer most probably has been or is currently a VR client, and is equally likely to be living independently as in a supervised setting (including with parents) at the time of first contact with an independent living center.

In addition to providing direct services to disabled consumers, the centers reported providing services to almost 14,000 nondisabled individuals (parents, friends). They also provided information and referral assistance to an additional estimated 56,000 individuals over the last year.

The above summary numbers of clients served are for the centers which responded to the survey questionnaires, some 121 of the 156 total centers funded under Part B. Extrapolations to the total population of Part B centers are feasible, if one multiplies the survey response aggregates by a factor of 1.28, representing the ratio of the total funding for Part B centers to the total Part B funding received by the centers which responded to the survey. The assumption is that the funding level of a center is an important measure of how much service and client and community impacts a center can achieve. (The analysis of nonresponse suggests no obvious differences between the 121 responding centers and the nonrespondents.) The respondent centers comprised 77.6% of all the Part B-funded centers, and 77.2% of the total federal funding for Part B centers; we thus will assume their achievements conservatively comprise 78% of the total achievements of Part B centers in services delivered and client and community impacts. Given this assumption, we would project that the overall Part B centers program nationally provided direct services to more than 61,400 disabled individuals, and to some 17,900 nondisabled individuals (parents, family), as well as information and referral-only assistance to an additional 71,700 individuals during the last year.

IV. SERVICES PROVIDED BY INDEPENDENT LIVING CENTERS

In section 711(c)(3) of the Act, Congress has called for a description of "the types of services provided by the independent living centers." This chapter describes the extent to which various types of services are provided, and variations in provision of services to different kinds of consumers. The legislative provisions suggest a range of possible services that centers might provide. These were specified in more detail during the development of evaluation standards. Standard 5 designates three services as fundamental or "core" services -- independent living skills training, advocacy, and peer counseling -- and suggests 11 other services which centers may choose to provide. Standard 6 designates information and referral as an additional primary service.

Services were grouped into major categories (such as housing or transportation, etc.) rather than identified as specific services within each category (such as housing modification or housing search assistance). If the latter approach had been used, the number of different services studied would have been prohibitive not only in terms of analysis but in terms of survey data collection burden. However, during site visits more detailed descriptions were obtained in order to provide examples of the service approaches being used.

The findings presented in this chapter are based on data collected through mail surveys of centers and consumers, which are supplemented by qualitative information collected during on-site visits. In the mail survey, centers were asked to provide data on the numbers of individuals receiving services in each category and the number of service units provided. As anticipated, in the absence of standardized reporting requirements there was variation across centers in the definition of units used to report service data. While several fairly common alternatives have emerged from the field (e.g., contacts, hours, and time increments), in total, more than 40 different types of service units were reported across all of the services and centers. No more than a third of the centers used the same unit measure to report services delivered for any of 18 services surveyed. (See the Standard 12 discussion of service unit data in Appendix D). Thus, it is infeasible to measure the extent to which services were provided by aggregating the number of units of services provided across centers. Most centers (over 80% for all but four of the services) providing each service, however, did provide data on the numbers of consumers receiving services. In addition, consumer mail survey respondents were asked to indicate the services they had received from the center.

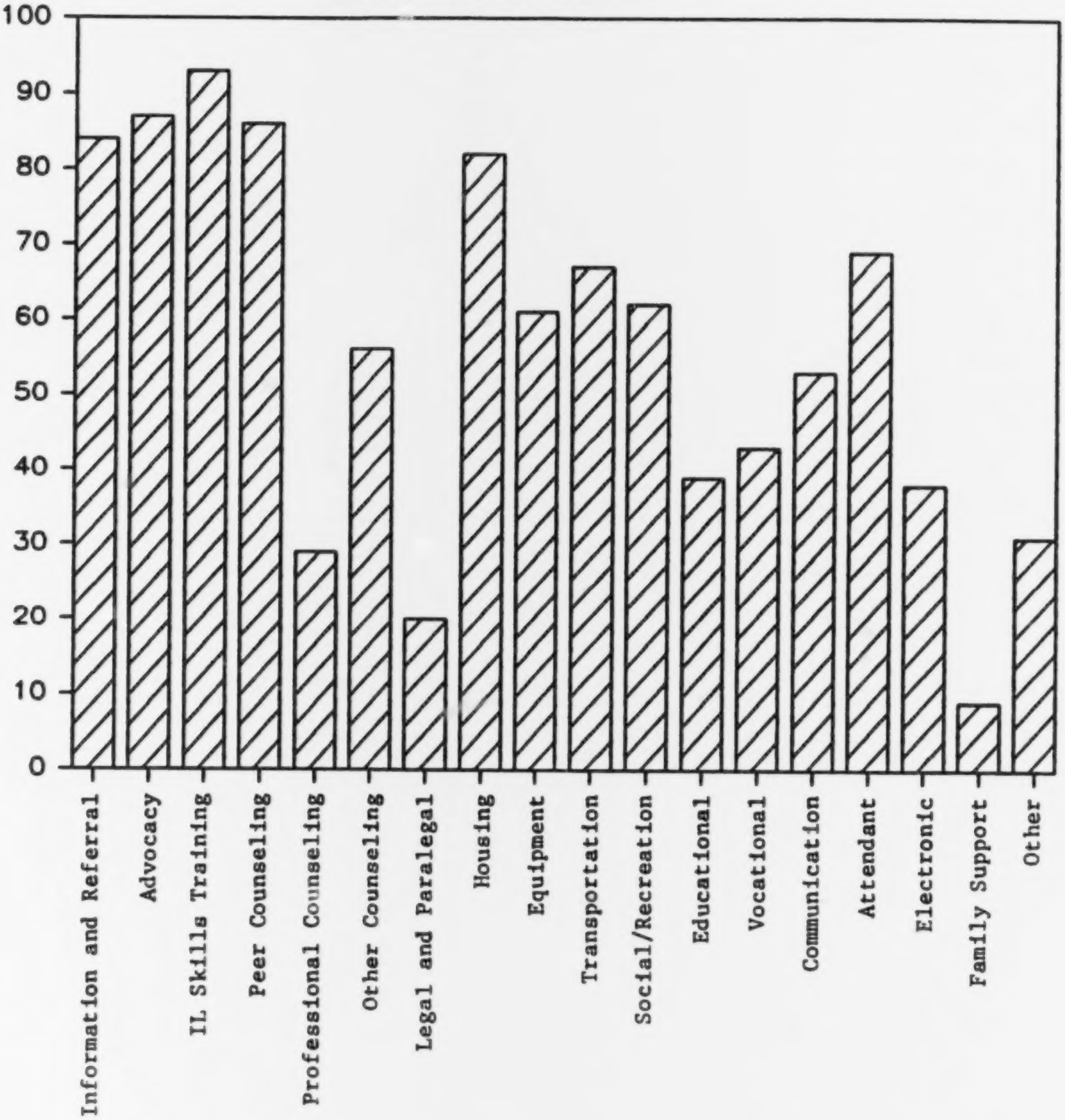
THE EXTENT TO WHICH "CORE" SERVICES WERE PROVIDED AND RECEIVED

Table IV-1 illustrates the broad range of services provided by the centers and the numbers of individuals reported by the centers as receiving each. While centers varied greatly in terms of the range and particular combinations of services they provided, there are a number of services that were common across most of the sample. The three services provided by the largest percentage of centers were independent living skills training (93%), advocacy (87%), and peer counseling (86%), the three services designated as "core" in the evaluation standards (see Figure IV-1). Moreover, 75% of the centers offered all three of these services.

While centers obviously varied in the number of consumers served in each area, depending upon center size and other factors, over the course of a year, centers provided advocacy services to an average of over 200 consumers (median = 80), and independent living skills training and peer counseling to over 100 consumers (medians = 70 and 40, respectively). The identification of these services as "core" services by the major

Figure IV-1

Percentage of Centers Offering Various Types of Services



constituencies involved in developing the evaluation standards underscores the fact that these services have emerged as common themes in the delivery of services to promote the achievement of independent living goals. However, the distribution of services received by consumers was somewhat different from that of services offered by centers (see Table IV-1). While the service received most frequently by consumers (independent living skills training) was also reported as being provided by the highest number of centers, more consumers reported receiving housing and social/recreation services than the two other "core" services (advocacy and peer counseling). Less than 50% of the consumers who responded to the survey participated in any of the core services (independent living skills training, advocacy or peer counseling). Thus, while these services from the centers' perspective seem to be necessary to meet the service needs of the consumer population as a whole, on an individual level they may not always be required. In fact, consumers tended to use a selection of services from among the many offered and seemed to vary widely in terms of the particular combination of services they used.

While the core services were offered by the majority of independent living centers represented in the study, site visit data revealed many variations in how these services have been defined, organized, and delivered by individual centers, as described in the following sections.

Advocacy

The concept of advocacy support to consumers has two dimensions. First, center staff encourage consumers to take action on their own behalf, assisting in problem solving, suggesting strategies, and, in some cases, providing formal advocacy training. This type of assistance is provided to consumers individually, as well as in group settings where peer interaction is felt to enhance the process. Second, the

Table IV-1

Types of Services Offered by Centers for Independent Living and Consumer-Reported Receipt of Services

Service	Center-Reported		Consumer-Reported
	% Centers Providing Service (N=121)	# Consumers Served	% Consumers Who Receive Services
IL Skills Training	93%	12,142	28%
Advocacy	87	20,142	23
Peer Counseling	86	10,855	28
Professional Counseling	29	1,297	--
Other Counseling	56	3,731	20[a]
Legal and Paralegal	20	1,294	8
Housing	82	9,606	29
Equipment	61	4,204	25
Transportation	67	9,162	29
Social/Recreation	62	4,534	29
Educational	39	2,337	14
Vocational Services	43	3,323	13
Interpreter/Reader/ Other Communication	53	4,673	6
Attendant/Homemaker	69	7,385	30
Electronic Services	9	616	5
Family Support Services	38	1,980	--
Information and Referral	84	52,395	64
Other	31	4,233	6

[a] Includes professional counseling and family support service categories.

center staff may take direct action on behalf of consumers when this seems appropriate, i.e., to make calls to or meet with relevant parties.

Advocacy was the service that centers reported providing to the largest number of consumers (20,142) other than information and referral. As illustrated in Table IV-2, advocacy services were used by all disability groups, although somewhat more by individuals with orthopedic impairments than other groups. Table IV-3 shows the statistically significant correlations between consumers' primary disabilities and the services they received. As shown in this table, there appears to be no significant differences in the use of advocacy services across disability groups.

Independent Living Skills Training

Almost all (93%) independent living centers offered some type of independent living skills training, but site visits highlighted substantial variations in who conducted the skills training, content, where training occurred, and the extent to which training is formalized. In some centers, there is a trend toward hiring registered nurses and occupational therapists to provide health- and self-care-related skills training. Other staff cover non-self-care areas related to consumer rights, financial management, or coping with personal issues. Some centers prefer to emphasize a peer role modeling service approach rather than offering skills training as a separate service because they feel that it puts staff in a teaching role, taking away from the "peer" aspect of the relationship.

Independent living skills training may occur at the center, in consumers' homes, or at a community location. Some centers visited offer training through groups, others only on an individual basis, while others offer both. There is a trend for centers who offer more structured types of skills training to develop formal written curricula or

Table IV-2

Extent of Consumer-Reported Receipt of Core Services by Primary Disability

Disability	Total	Percent Consumers Receiving		
		Advocacy	ILS Training	Peer Counseling
Visual Impairment	210	22.9%	33.3%	25.2%
Hearing Impairment	126	17.5	27.0	21.4
Orthopedic Impairment	676	26.0	25.6	28.3
Mental Illness	54	22.2	44.4	40.7
Mental Retardation	52	17.3	61.5	23.1
Other Disabling Conditions	260	21.5	31.2	26.9
Multiple Disabilities	169	18.3	30.8	23.7
All Clients	990	23.0	28.2	28.0

Table IV-3

Relationship Between Primary Disability and Consumer Participation in Services[1]

Services Received/ Disability	Visual Impairment	Hearing Impairment	Orthopedic Impairment	Mental Illness	Mental Retardation	Other Disabling Conditions
I and R	.028				-.009*	
Advocacy						
ILS Training				.008*	.001*	
Peer Counseling		-.045		.014*		
Other Counseling	.008*					.027
Legal		.007*			-.049	
Housing						
Equipment	.027			-.044	-.001*	-.001*
Transportation						
Social/Recreational		-.040		.046	.006*	
Educational					.003*	
Vocational				.001*		
Communication	.005*	.001*				
Personal Assistance		-.034			-.004*	
Electronic	.007*	.011			-.040	
Other	.037					.038

[1] based on Pearson Correlation Coefficients; relationship significant at .05 level

*Relationship significant at .01 level

training sequences, especially if they offer training in groups. These centers reported greater success in obtaining fee-for-service funding from other agencies than centers with more informal or unstructured approaches to independent living skills training.

In addition to being the service that is offered by the greatest number of centers, independent living skills training is also the service which the largest proportion of consumers reported receiving (28.2%). As shown in Table IV-2, independent living skills training was received by at least one-fourth of every disability group, and by even larger proportions of individuals who are mentally retarded or mentally ill.

Peer Counseling

The central concept in peer counseling is that persons with disabilities who have struggled for independence can best help others who are trying to cope with that struggle. Peer role modeling is thus at the heart of the peer counseling process. As with the other core services, however, site visits highlighted extensive variations in how this service is implemented. One area of variation is in the definition of "peer," or who delivers peer counseling services. In some centers, peer counselors are unpaid volunteers who work with their disabled peers under the supervision of center staff, or as part of a network of peers who are available to each other for mutual support within the disabled community. As unpaid volunteers, they remain true peers by remaining distinct from paid staff. In other centers, paid staff with disabilities provide peer counseling, and in some cases are required to have counseling or other professional qualifications. There are also varied degrees of emphasis on the disability of the peer counselor, with some centers carefully matching like disability types, others encouraging consumers to get to know individuals with other types of disabilities, and still others determining the importance of disability-matching according to the consumer's specific objectives for the peer relationship.

A second area of variation in peer counseling approaches explored during the site visits was in how services are provided. In some centers, peer counseling sessions are set up on a regular basis in much the same way as more traditional professional counseling services, while in others peer discussion groups may convene, or one-on-one counseling might occur on a more irregular, as-needed basis. In some cases peer counseling is highly structured, with establishment of specific counseling goals and careful monitoring of progress. Finally, in some centers, peer counseling is viewed as occurring naturally as part of the service delivery process involving all staff with disabilities in their ongoing work with consumers, rather than as a distinct service component.

Peer counseling services were provided by 86% of the centers surveyed, and were received by almost as many consumers as received independent living skills training (28%). As shown in Table IV-2, peer counseling services were received by over one-fifth of individuals in every disability group, with somewhat more utilization by individuals having mental illness as their primary disability (40.7%). Table IV-3 confirms that this is a statistically significant relationship, and indicates that individuals with hearing impairments were less likely to receive peer counseling services than other groups. This confirms site visit findings that individuals with hearing impairments continue to receive many of their services through other programs and, while often relying heavily on indepenent living centers for specific services, tend to be part of a somewhat insular community and participate less in more interactive services such as counseling and recreation.

Information and Referral

In addition to the three core services defined in Standard 5 (advocacy, independent living skills training, and peer counseling), information and referral was also designated as an additional primary service. Centers reported providing information and referral assistance to an average of over 200 individuals per year, a much larger number than any other service. Many of these individuals received only I & R services and are not considered by most centers to be consumers in the same sense as individuals receiving other, more direct services. Many centers visited did not follow a formal intake procedure for individuals merely requesting information and referral, and some did not bother to collect identifying or demographic information. Other centers placed a greater emphasis on I & R and used follow-up procedures to track the extent to which individuals' I & R needs were met. In fact, some centers encouraged individuals who requested I & R more than once to go through the regular intake assessment process because repeat I & R users often had unmet needs that the center could help with more directly.

The consumer sample was constructed to exclude "I & R only" consumers because: (1) it was expected that I & R by itself would contribute only indirectly to outcomes, (2) identifying the sample would have been impossible for those centers who do not collect identifying information from I & R callers, and (3) it was anticipated that individuals with such limited contact with the center would be less likely to take the time to complete and return the survey. However, consumers of direct services also make use of I & R assistance. Almost two-thirds (64%) of the consumers responding to the mail survey reported having received I & R assistance.

OTHER TYPES OF SERVICES PROVIDED

Legal and Paralegal Services

Legal and paralegal services are provided to assist consumers in administrative appeal processes and protecting legal rights. Some of the centers visited provided consumers with the information needed to enable them to act on their own behalf in matters that involve an appeal or legal process. Often the matters of concern related to financial benefits or social assistance programs with clearly specified appeal processes. In other centers, staff reported assisting more directly, acting on behalf of the consumer, and may have consulting arrangements with an attorney in the community for more complex issues. Center survey data indicates that 20% of centers provided some form of legal or paralegal assistance. Only 8% of consumer respondents reported receiving legal or paralegal services.

Housing

Referral service to accessible and/or subsidized housing in the community was the most frequently cited form of housing assistance mentioned by the centers visited. This service often also included assisting consumers to obtain eligibility for subsidized housing and developing extensive relationships with property owners and housing assistance agencies. Another approach employed by centers to maximize housing options was to provide roommate matching services. Some centers had special funds to assist consumers in making necessary home modifications, others referred consumers to available resources in the community. While obtaining permanent housing was the goal of most housing efforts, some centers maintained directories of emergency housing services and hotels. Emergency housing vouchers, often coordinated through local welfare agencies, were provided in emergency situations for short-term stays.

A few centers provided housing directly, either on-site (often as part of a program coordinated with an umbrella agency) or in selected housing facilities in the community. Housing services were provided by most centers (82%), and these services were received by 29% of the consumer respondents. As shown in Table IV-3, there were no significant correlations between type of disability and whether housing services were received.

Equipment

Most equipment services to consumers involved loaning or maintaining and repairing mobility and assistive aids such as wheelchairs, walkers, and commodes. Centers also served as a referral source for consumers interested in obtaining or selling used equipment. A majority of centers (61%) reported providing equipment services to consumers. One-quarter of the consumers responding to the consumer survey reported receiving these services. Consumers with visual impairments were more likely than other disability groups to use equipment services, while those with mental illness were less likely to use these services.

Transportation

Some centers which were visited provided transportation directly and operated vehicles primarily used to transport consumers to the center for appointments and activities. In a few centers, a center van was also used to transport consumers to medical appointments. Site visits revealed, however, that insurance and maintenance costs have forced some centers to discontinue provision of this service. Instruction and information about available accessible private and public transit services was another transportation service offered to consumers. However, some communities had limited options for consumers and the lack of accessible public transportation remained a serious problem. Transportation services were provided by 67% of the centers. Twenty-nine percent of consumers reported that they received transportation services.

Social and Recreational Services

Formal and informal opportunities for socialization were provided by many centers. Some centers visited reported regularly scheduling social or recreational events for consumers. Centers provided encouragement for consumers to engage in activities they might not pursue ordinarily because of physical limitations. Some centers were also important clearinghouses for information about recreational activities at the community and state level that are specially adapted to encourage participation by disabled people. Social and recreational activities were provided by many of the centers (62%). Consumer Mail Survey data indicates that 29% of respondents participated in social and recreational activities offered by their centers.

Educational Services

Some centers offered services to assist consumers in pursuing their educational goals. These varied from assisting families of disabled children with the IEP process, to providing educational counseling and learning support services to college students. One center visited also offered remedial education to adults wishing to complete their high school equivalencies. Educational services were provided by 36% of the centers. Fourteen percent of consumers responding to the survey reported receiving educational services.

Family Support Services

Geared to family members of disabled consumers, these services provide counseling support and information. The transition to independent living is often facilitated for many consumers by family understanding and support. This service was provided by 30% of the centers.

Vocational Services

Most centers that provided vocational services did not have multi-level vocational programs that work with consumers at all stages of vocational development. The few that did were often part of umbrella agencies that had long-standing vocational programs. Centers often coordinated services with other agencies, such as the state VR agency and local employment development programs. A few centers offered pre-vocational adjustment programs to prepare consumers for training. Other centers assisted consumers with resume writing and job search skills and provided placement follow-up services. A few centers had received grants to start specialized training programs in areas such as computer training and telephone answering or to develop training programs for specific disability groups. Vocational services were provided by 43% of centers and received by 13% of consumer respondents.

Interpreter, Reader, and Other Communication Services

The most common communication service provided by centers visited was telephone assistance for hearing-impaired consumers through TDD relay. The center was often a consumer's primary mechanism for information exchange. Some centers also provided interpreter services for hearing-impaired consumers, or maintained referral lists of interpreters. In addition, many centers assisted consumers with visual impairments through braille services and reader referral. Slightly more than half (53%) of the centers provided communication services. Only a small percentage (6%) of consumer respondents reported receiving communication services.

Attendant and Homemaker Services

Most of the centers visited provided attendant and homemaker services through maintaining a registry of available attendants for consumers to hire. While centers recruited and screened potential attendants, it was most often the consumer's responsibility to select and approve the attendant. Many centers provided consumer training in selecting and managing attendants. Consumer manuals are often developed by centers for this purpose. Some centers ran training programs for attendants to increase the attendants' knowledge of disability-related issues and to teach attendant care skills. A few centers administered personal care attendant funds directly and determined consumer eligibility. Slightly over two-thirds (69%) of the centers provided attendant and homemaker services and almost one-third (30%) of consumer respondents reported receiving such services.

Electronic Services

Electronic services involve providing consumers information about, access to, or loan of electronic equipment such as specially adapted computers or environmental control systems. Only 9% of centers provided this service to consumers, and only 5% of the consumers in our sample reported that they received such assistance.

CENTER SERVICE PHILOSOPHY

While many of the services described above are similar to services provided by other social service agencies, the delivery of services through the Centers for Independent Living Program is considered distinct from other approaches in terms of service philosophy. The evaluation standards specify several components of this service philosophy considered important to the program: use of peer role models, promotion of self-help and self-advocacy, consumer definition of his or her own service objectives, and consumer control of his or her own service delivery. As shown in Table IV-4, centers generally reported a high degree of emphasis on these service approaches, with 93% of respondent centers reporting a strong emphasis on use of peer role models, and 97% strongly emphasizing consumer self-help and self-advocacy. Data from the community agencies confirmed that the independent living service philosophy was indeed emphasized by most centers (Table IV-5).

SUMMARY

The Title VII Part B Centers for Independent Living offered a wide range of different types of services, with variations in how individual services were provided, and in how service records were maintained. Almost all centers offered each of the "core" services identified as fundamental services in the evaluation standards (independent living skills training, peer counseling, and advocacy), and three-fourths provided all three of these services. On the other hand, less than half of the consumers surveyed received any of these services. Thus, while it may be essential that centers offer this set of services, they are not necessarily "core" from the individual consumer's viewpoint, given the diversity of consumer needs.

Most centers offered information and referral services, as stipulated in Standard 6. Almost two-thirds of direct service consumers also received I & R services, in addition to the many individuals receiving only I & R services who were not surveyed by the evaluation and, in many cases, who were not identified or counted as consumers by the centers they contacted.

Table IV-4

Center-Reported Emphasis on Independent Living Service Philosophy

Philosophy Component	% of Agencies Giving High Rating (4 or 5)* (N = 121)	Mean Rating*
Peer role models	93%	4.6
Self help and self advocacy	97	4.7
Consumers define own service objectives	82	4.3
Consumers control of own service delivery	81	4.2
Average across all four components	—	4.5

*Based on rating scale of 1 (not an emphasis) to 5 (strong emphasis).

Table IV-5

Community Agency Assessment of Center Emphasis on Independent Living Service Philosophy

Philosophy Component	% of Agencies Giving High Rating (4 or 5)* (N = 100)	Mean Rating*
Peer role models	75%	4.1
Self help and self advocacy	84	4.2
Consumers define own service objectives	59	3.8
Consumers control own service delivery	51	3.6
Average across all four components	—	3.8

*Based on rating scale of 1 (not an emphasis) to 5 (strong emphasis).

All but one of the other 11 services included in the evaluation standards (professional and other counseling, legal and paralegal services, housing, equipment services, transportation, social and recreational services, education, family support, vocational services, interpreter and communication services, attendant and homemaker services, and electronic services) were provided by at least a fifth of respondent centers.

V. CONSUMER OUTCOMES

Perhaps the most important aspect of evaluating the Centers for Independent Living Program is the assessment of its affects on individuals receiving services. In Section 711(c)(3) of the Act, Congress asks "how services provided contributed to the maintenance of or the increased independence of handicapped individuals assisted."

Unfortunately, there are no simple and widely accepted measures for the outcomes of independent living efforts akin to the employment and earnings measures used for vocational rehabilitation programs. Historically, independent living programs have focused their data collection and reporting efforts largely on numbers of individuals served and the number of contacts or units of service provided. After much consideration, the National Council's Standard 3 calls for assessing increased consumer achievement of independent living goals in areas "such as, but not limited to" 20 different areas.

This chapter reports on the achievement of consumer outcomes in these many varied areas. Achievement is measured in several ways. First, in the center mail survey all centers were asked to report the number of consumers achieving specific positive outcomes based on center records. Accountability for specific consumer outcomes represented a dramatic departure for many centers from their traditional data collection and reporting practices. Even those centers which were already monitoring outcomes did not have data collection and monitoring procedures designed to provide direct data for each of the areas of concern in the evaluation standards. Thus, a data category used by a center might merge several of the requested categories into one. Still other centers may have lacked some data items altogether, lacked an ability to readily access their data, or perhaps not have targeted that type of consumer goal. Estimates were permitted in these cases but reanalyzed by the evaluation to ensure consistency with other data reported and with site visit observations. (The analysis found no significant differences in levels of achievement between those centers using exact records and those providing estimates, suggesting that estimating produced no obvious bias towards over- or under-reporting.)

Because the lack of common outcome measures was anticipated, the study also collected survey data directly from the consumers themselves. The consumer mail survey examined outcomes in two ways. One group of questions asked consumers whether they improved or maintained their situations in five key areas (housing, education, employment, income, and transportation) since first contact with the center, and the extent to which the center helped to bring about any improvements. A second group of questions probed a wide range of other gains that consumers might have experienced in the areas specified in the standard.

CENTER-REPORTED OUTCOMES

Table V-1 summarizes consumer achievements as reported by the centers. Over 58,000 positive outcomes were reported by the responding centers, in many different forms.[1] The most frequently reported achievement is securing services for consumers through referral to other programs, reflecting the extensive information and referral efforts observed during the site visits. (These referrals are in addition to other assessment, case management, counseling, and other services received by the consumer from the center; consumers who receive only referral services (I & R) are not considered clients of the centers in this analysis and are not included in the counts of outcomes being reported here.) Over 5,000 consumers were reported as achieving each of the following outcomes: learned to use public or other transportation, obtained financial benefits, acquired assistive mobility and/or communication aids, acquired attendants or homemakers, and acquired

Table V-1

Consumer Outcomes Reported by Centers for Independent Living

Type of Outcome	# of Consumers Reported as Achieving Outcomes	% of Total Outcomes Achieved
Obtained Housing Modifications to Improve Accessibility	2,254	3.9%
Moved from Institution to Less Restrictive Setting	2,030	3.5
Obtained Financial Benefit	5,542	9.5
Learned to Use Public/Other Transportation	5,941	10.2
Acquired License to Drive	264	.5
Acquired Attendants, Homemakers, Etc.	5,033	8.6
Acquired Readers or Interpreters	5,021	8.6
Obtained Services by Referral to Another Program	15,210	26.1
Became Able to Carry Out Household Chores	3,653	6.3
Acquired Mobility, Communication or Visual Aids	5,472	9.4
Achieved Educational Goals	1,818	2.7
Obtained Employment	1,548	2.7
Registered to Vote	2,639	4.5
Gained Membership in Community Groups	1,170	2.0
Other Outcomes	692	1.2
TOTAL	58,287	100.0%

readers or interpreters. Over 3,500 consumers were reported to have become able to carry out household and shopping chores. Well over 2,000 consumers were reported as moving out of institutions into more independent living situations. Even though employment is not commonly seen as a major objective of center services, centers on average each assisted 13 individuals a year to secure employment -- presumably by supplementing the services of vocational rehabilitation programs with additional independent living services. They each on average also helped deinstitutionalize 20 individuals a year.

The diversity of outcomes reported by the centers illustrates a basic difficulty in evaluating independent living services -- that each disabled individual presents a somewhat different constellation of needs and thus has different goals appropriate for services and achievement. Centers beginning to develop their own outcome measurement systems tended to focus on individual goal achievement measures in order to reflect the individualized nature of the program. Some used individualized written independent living plans (IWILP) akin to the individualized written rehabilitation plan (IWRP) used in VR programs. However, center staff reported that the process of identifying intended outcomes for independent living services was often very different from the IWRP process. Consumers of independent living services were less likely to have a clear idea of their goals than VR consumers, and many found the concept of goalsetting to be unfamiliar if decisions had previously been made on their behalf by someone else. Often goal planning was an evolutionary process rather than a first step. Sometimes the establishment of goals was an outcome in and of itself.

CONSUMER-REPORTED OUTCOMES

The consumer survey also reflects the diversity in consumer goals, but has the advantage of being able to comprehensively gather similar data from all consumers regardless of the information system that may have been used at the center where the consumer received services. (The Consumer Mail Survey instrument is included in Appendix B.) Consumers were asked if they had experienced improvements in their housing, education, employment, income or transportation situations. They were also asked if contact with the center had helped them to experience gains in knowledge, skills, aids, benefits or services, or personal/social growth. Over 90% (91.5%) of the consumers responding to the survey reported gains in at least one area.

In addition, the survey asked consumers if their own major purpose in seeking center services was to gain additional independence or to maintain a current level of independence. Nearly one-third (32%) identified themselves as "gain" consumers, 38% reported they were trying to maintain independence, and the remainder were seeking information or had other purposes. Further analysis shows that "gain" consumers tend to be younger than "maintenance" consumers and more frequently received independent living skills, housing, transportation, education, vocational, and personal assistance services than "maintenance" consumers. Maintenance consumers were more likely to be those who became disabled as adults.

Table V-2 summarizes consumer responses about whether they had experienced improvements in their housing, education, employment, income, or transportation situations during contact with the center, and whether they believed the center helped them in making the gains they achieved. Almost 75% of the respondents reported improvements in at least one of these five areas, with almost two-thirds (65%) crediting the center with helping make at least one of the improvements. Housing was by far the area in which most disabled consumers reported gains, with 69% reporting that their current housing situation allowed more independence (such as through increased accessibility or a move to a new

Table V-2

Consumer-Reported Improvements or Maintenance of Situation

Area of Improvement	Reported Improvement			Reported ILC Help in Improving Situation		
	# of Consumers	Total N*	% of Consumers	# of Consumers	Total N*	% of Consumers
Housing	578	841	69%	292	875	33%
Education	221	909	22	107	906	12
Employment	105	892	12	78	897	9
Income	296	917	32	97	912	11
Transportation	237	915	26	224	925	24
At Least One Improvement	740	990**	75	478	740**	65

Area of Improvement	Reported Maintenance of Current Situation			Reported Either Improved or Maintained Situation		
	# of Consumers	Total N*	% of Consumers	# of Consumers	Total N*	% of Consumers
Housing	150	841	18%	728	841	86%
Education	688	909	76	909	909	100
Employment	700	877	80	805	877	91
Income	532	907	59	828	907	91
Transportation	619	911	68	856	911	94
Maintained three or More	590	990**	60	---	---	---
Maintained All of the Above	68	990*	7	---	---	---

*"Total N" includes consumers responding "yes," "no," or "not applicable" to questions about changes in situation.

**Also includes missing cases.

residence). Even though employment is generally not thought to be a priority among independent living service consumers, more than 12% of the consumers reported an improved employment situation (e.g., had become employed, had increased hours of employment, had become employed at a more desirable job).

The consumer evaluation of the helpfulness of center services in achieving situation improvements varied across types of improvements. Most consumers did credit their transportation (96%) and employment gains (72%) to center services, half credited center services for their housing and educational gain, and only 33% credited center services for their income gains. This suggests a realistic differentiation by disabled consumers of those improvements in their lives which may have been due to the centers' assistance and those which were likely to have been influenced by other factors (e.g., cost of living increases in SSI payments).

The consumer survey data also provide estimates of the numbers of individuals who maintained their current situation since the time they first contacted the center. Consumers were considered to have maintained their situation if they reported that their current situation was neither better nor worse than when they first had contact with the center. As illustrated in Table V-2, on average, 93% of consumers reported that they had either improved or maintained their current situation in each of the five areas.

Tables V-3 through V-6 summarize the consumer responses concerning a broad range of additional gains and improvements which they explicitly attributed to center services. Four general categories of change were probed in the survey: personal and social changes (Table V-3); increased knowledge of the type likely to facilitate independent living (Table V-4); increased skills in meeting their own needs (Table V-5); and the receipt of aids, benefits and services (Table V-6). Within each

Table V-3

Consumer-Reported Personal or Social Changes Through Contact with Center

Area of Change	# of Consumers Reporting Change	% of Consumers Reporting Change
More Comfortable in Public	427	48.6%
More Comfortable Socially	375	42.7
Cope Better with Disability	454	51.5
Feel Better Regarding Sexuality and Relationships	255	28.9
Belong to More Community Groups	177	20.1
Have More Friends	325	37.0
Feel More Self-Confident	488	55.6
More Assertive	402	45.7
Participate in More Sports	157	17.8
More Healthy and Physically Fit	240	27.3
Other Changes	75	9.2
Reported at Least One of Above	676	68.3

Table V-4

Consumer-Reported Gains in Knowledge Through Contact with Center

Area of Knowledge	# of Consumers Reporting Change	% of Consumers Reporting Change
Education/Training Opportunities	312	35.5%
Employment Opportunities	219	24.9
Affirmative Action	193	21.9
Benefit Programs and Financial Assistance	317	36.0
Housing Options and Home Accessibility	337	38.3
Personal Health	283	32.2
Personal Care Assistance	359	40.0
Equipment Options	326	37.1
Social/Recreational Activities	340	38.7
Transportation Options	334	38.1
Other Knowledge	42	5.2
Acquired at Least One of the Above	643	75.1

Table V-5

Consumer-Reported Skills Acquired Through Contact with Center

Type of Skill Acquired Through Center Assistance	# of Consumers Reporting Skill	% of Consumers Reporting Skill
Ability to Confront Infringement of Rights	334	38.2%
Manage Personal Finances	216	24.7
Acquire Medical/Community Services	328	37.4
Carry out Household and Shopping Chores	252	28.8
Acquire Household Support Services	229	26.2
Manage Self-Care Routine	226	25.8
Manage Attendants	244	27.9
Use Equipment/Aids	222	25.4
Use Community Resources	317	36.1
Acquire/Use Transportation	298	34.0
Develop Career or Life Goal Plan	208	23.7
Other Skills	48	5.9
Acquired at Least One of the Above	693	70.0

Table V-6

Consumer-Reported Aids, Benefits and Services Received Through Contact with Center

Aids, Benefits, or Services Received Through Center Assistance	# of Consumers Receiving Services	% of Consumers Receiving Services
Attendant	267	30.9%
Reader	32	3.7
Interpreter	40	4.6
Mobility Aid	179	20.8
Communications Aid	98	11.4
Adaptive Equipment	120	13.9
Equipment Rapair	153	17.8
Legal Services	199	23.1
Other Aid or Service	112	13.7
Received at Least One of Above	614	62.0

category, nine to 12 specific areas of change were probed. Overall, 89% of consumers reported at least one change across the four areas. There was relatively little variability across the four general areas, with 62 to 75% of consumers reporting at least one gain in each area. The average number of changes for each consumer was one to three in each of the four general areas: personal/social changes (3.4 changes on average), aids (1.2 changes), skills (3.0 changes), and useful knowledge (3.1 changes). The most frequently reported achievements were within the personal/social change cluster (Table V-3), with the majority of consumers reporting greater self-confidence (56%) and coping better with being disabled (52%) as a result of their center contact. When asked about knowledge gained (Table V-4), consumers most frequently reported having learned about social/recreational activities (39%), housing (38%) and transportation options (39%). The three most frequently acquired skills reported by consumers (Table V-5) were skills in confronting infringement of rights (38%), acquiring medical and community services (37%), and learning how to use community resources (36%). The most frequently reported aids, benefits or services (Table V-6) were attendant services (31%), legal or advocacy services (23%), and mobility aids (21%).

The review of Standard 3 in Appendix D presents in detail the large variety of outcomes probed in the context of the 20 areas of improvement laid out in the standard. For each area, at least 20% of consumers reported improvements on at least one outcome related to that area. One-third or more of the consumers reported gains in 11 of the areas: living arrangements (69%), self-direction (66%), personal growth (57%), social skills (49%), communication (46%), personal care (41%), recreation (39%), housing (38%), transportation (38%), assistive devices (37%), education (36%), and income and financial management (36%).

As an overall summary question about the impact of center services, consumers were asked to rate on a scale of 1 to 5 the extent to which they perceived the centers as helping increase their independence. A majority (57%) gave the maximum "5" rating, and 78% gave ratings of "3" or above.

FACTORS CONTRIBUTING TO SUCCESS

Tables V-7 through V-10 summarize the findings of the multivariate analysis described in more detail in Chapter IX and Appendix E. As illustrated in these tables, the most important factors contributing to consumer outcomes were the services received. Organizational and consumer characteristics also had an effect on some outcomes, although most factors tended to have a positive effect on some outcomes and a negative effect on others.

Which Services Made the Biggest Difference to Consumer Outcomes?

As illustrated in Table V-7, all of the services received by consumers had a positive effect on consumer achievement in at least one of the consumer-reported outcome areas. However, some differences in effect were observed. Housing services had the greatest observed effect, as they were associated with greater achievement in all seven consumer reported outcome areas. Advocacy, independent living skills training, peer counseling, and equipment services also were each positively associated with four of the seven areas. Vocational, electronic and "other" services had more narrow effects, each affecting only one outcome area. None of the services were negatively associated with achievement in any of the outcome areas, with the exception of legal services, which was negatively associated with situational improvements. This may simply reflect the fact that consumers requiring legal assistance may face greater barriers than those not needing legal help, or

Table V-7

Effect of Services Received and Service Characteristics Upon Consumer-Reported Outcomes[a]

Characteristics	# of Outcomes Positively Associated	# of Outcomes Negatively Associated	# of Outcomes Unrelated
Service Received:			
Information and Referral	2	0	5
Advocacy	5	0	2
ILS Training	4	0	3
Peer Counseling	4	0	3
Other Counseling	3	0	4
Legal	3	1	3
Housing	7	0	0
Equipment	4	0	3
Transportation	3	0	4
Social/Recreational	3	0	4
Educational	3	0	4
Vocational	3	0	4
Communication	2	0	5
Personal Assistance	3	0	4
Electronic	1	0	6
Other	1	0	6
Service Characteristics:			
Frequency of Contact	5	0	2
Personal/Direct Center Contact	4	0	3
Length of Service Period	3	0	4
Long Service Period (4+ years)	0	4	3
Case Management	6	0	1
Staff with Similar Disability	0	1	6
Staff with Different Disability	3	0	4
Consumer Volunteered at Center	3	0	4
TOTAL	75	6	87

[a] Based on multivariate analysis.

Table V-8

Effect of Services Offered Upon Center-Reported Outcomes[a]

Service Offered	# of Outcomes Positively Associated	# of Outcomes Negatively Associated	# of Outcomes Unrelated
Advocacy	1	2	4
ILS Training	2	1	4
Peer Counseling	1	1	5
Legal	2	1	4
Professional Counseling	1	2	4
Other Counseling	1	2	4
Housing	2	0	5
Equipment	0	4	3
Transportation	2	1	4
Recreation	2	1	4
Educational	1	2	4
Vocational	1	0	6
Communication	0	2	5
Attendant	2	3	2
Electronic	3	1	3
Family Support	2	1	4
I & R	1	3	3
Other	1	2	5
TOTAL	25	33	69

[a] Based on multivariate analysis.

Table V-9

Effect of Consumer Characteristics Upon Consumer-Reported Outcomes[a]

Characteristics	# of Outcomes Positively Associated	# of Outcomes Negatively Associated	# of Outcomes Unrelated
Consumer Characteristics:			
Past Work History	0	1	6
Age	0	1	6
Sex-Female	1	0	6
Minority/Ethnic Group Member	0	0	7
Time Since Onset of Disability	2	0	5
Living in Supervised Setting	7	0	0
Living with Parent(s)	4	0	3
VR Client Status	6	0	1
Someone Else Completed Survey	0	6	1
Goal of Improving versus Maintaining	2	1	4
Presence of Disability:			
Severity of Disability	1	1	5
Visual Impairment	3	3	1
Hearing Impairment	0	0	7
Mental Illness	1	1	5
Mental Retardation	1	5	1
Other	2	0	5
TOTAL	30	19	63

[a] Based on multivariate analysis.

Table V-10

Effect of Center Characteristics and Management Practices Upon Center- and Consumer-Reported Outcomes[a]

	Center-Reported Outcomes			Consumer-Reported Outcomes		
Characteristics	# of Outcomes Positively Associates	# of Outcomes Negatively Associated	# of Outcomes Unrelated	# of Outcomes Positively Associated	# of Outcomes Negatively Associated	# of Outcomes Unrelated
Center Characteristics:						
Free-Standing Agency	3	2	2	0	0	7
Total Agency Budget	3	3	1	3	0	4
Years in Operation	2	0	5	2	0	5
Part B as % of Budget	0	2	5	3	0	4
Community Development as % of Effort	0	0	7	1	0	6
Rural Service Area	0	3	4	0	1	6
Disabled Director	1	0	6	1	2	4
Disabled Staff	3	0	4	0	3	4
Direct Grantee	3	0	4	0	3	4
Nonprofit Organization	0	0	7	2	3	2
Partial State Service Area	3	2	3	0	0	7
Percent of Consumers Referral Only	0	6	1	1	2	4
Disabled Board	2	2	3	0	3	4
IL Philosophy	2	4	1	5	0	2
Center Management Practices:						
Defines Specific Service Objectives	1	1	5	2	2	3
Determines Average Cost Per Service	1	1	5	2	0	5
Documents Consumer Goal Achievement	0	1	6	2	0	5
TOTAL	25	25	69	24	19	76

[a] Based on multivariate analysis.

have complex problems. Table V-8 shows that whether or not a center offered a given service was not consistently related to center-reported outcomes. This is partially due to the fact that center data do not allow testing direct relationships between services and outcomes. Centers were only asked which services they offered, not which services were used by their consumers achieving gains. It is important to note, however, that centers offering a broad array of services tended to have higher outcomes. Generally, services received by consumers had the most statistically significant impact on outcomes, relative to consumer and center characteristics. (See Chapter IX for a fuller explanation of this finding.)

For Which Kinds of Consumers Were Centers Most Successful?

Because consumers varied so much in their needs and goals, consumer characteristics that appeared related (in a statistically significant way) to one kind of outcome proved unrelated to another outcome (see Table V-9). Several general patterns across many (though never all outcomes) were apparent, however:

- Older consumers were less likely to improve and more likely to maintain their current situations. Younger consumers were more likely to experience personal/social changes than older consumers.
- Consumers who are currently or were previously Vocational Rehabilitation clients were more likely to experience gains than other consumers.
- Type of disability generally made few consistent differences in achievement. However, consumers with mental retardation were less likely to achieve outcomes in most areas (although more likely to achieve personal/social changes than other groups). Other disability groups were

more likely to report having experienced gains in some areas, while less likely in other areas (see also Table IX-4).

- Consumers living in more restrictive and supervised settings were more likely to report gains than other consumers. Consumers living with their parents were more likely to report gains on some outcome measures. (Such consumers were more likely to have an identified goal of improvement rather than maintenance, and were likely to have greater needs and room for improvement than individuals already living independently.)
- The severity of a consumer's disability, as measured by a composite of a variety of proxy measures (see Chapter III) was not associated with consumer outcomes for most measures, though it was negatively related to some situational improvements (like housing), and positively related to gains in skills. Individuals with the most severe disabilities, as indicated by the need for someone else to complete the survey on their behalf, were less likely to experience gains than other consumers.

Thus, the centers appear to be effective for a broad range of consumers both in increasing and maintaining their independence. The consistently positive relationship between VR client status and outcomes suggests that the combination of services from both types of programs may be particularly effective.

What Kinds of Centers Were Most Successful in Assisting Consumers to Achieve Independent Living Outcomes?

Because the center-reported data are based on 121 centers, while the consumers surveyed represent only 36 centers, the relationships between center characteristics and outcomes are more powerful when using the center-reported outcome data. Table V-10 summarizes these relationships. The major findings of the multivariate analysis include:

- Centers with a higher percentage of disabled staff had higher number of gains, even when controlling for service and consumer characteristics. Also, consumers reported higher outcomes when the staff they worked with at the center were disabled.
- There was no conclusive evidence that either the presence of a disabled director or a disabled majority on the board of directors was essential to center success.
- Centers less dependent on Part B funding reported a higher number of individuals acquiring attendants and obtaining employment than those receiving a larger proportion of their funding from Part B.
- Direct grantees tended to report a higher number of outcomes than centers receiving their funds through VR subcontractors.
- Those centers with a strong independent living philosophy (as defined in Standard 1) reported fewer consumer gains than centers with less emphasis on independent living philosophy, although consumers reported more gains if they worked with centers which strongly emphasized independent living philosophy.

Thus, while overall, centers with a greater degree of consumer participation in service delivery report higher outcomes in a number of areas than centers with fewer disabled individuals involved, the importance of disabled directors and consumer-controlled boards was inconclusive. The negative relationship between independent living philosophy may reflect less emphasis on data collection and reporting procedures among centers that stress consumer self-help and de-emphasize more traditional case monitoring and documentation approaches.

FOOTNOTE

[1] An analysis of nonresponse suggests no obvious difference between the 121 responding centers and the nonrespondents. Outcomes for the total program (156 centers) can be estimated by simply multiplying center-reported outcomes by a factor of 1.28, the ratio of center funding to respondent funding.

VI. CONSUMER PARTICIPATION IN THE CENTERS

Congress first identified consumer participation to be a key element of the Centers for Independent Living Program by requiring it as a condition of funding in the 1973 legislation. Section 711(c)(3) of the Rehabilitation Act of 1973 as Amended stipulates that grant applications "provide assurances that handicapped individuals will be substantially involved in policy direction and management of such center, and will be employed by such center." Thus, the evaluation as mandated in the 1984 amendments act calls for an assessment of the "extent to which handicapped individuals participate in management and decision-making in the center." Reflecting the self-help orientation of the centers, these provisions are based on the assumption that individuals with disabilities recognize their own needs and are best-suited to articulate how centers might meet those needs. The evaluation standards were still more specific about the nature and degree of consumer participation. Standard 8 stipulates that the evaluation assess whether disabled individuals are "substantially involved in the policy direction, decision-making, service delivery, and management of the center, and given preference as: members of Boards of Directors (at least 51% qualified disabled persons), managers and supervisors, and staff."

The findings presented here are based on data collected through mail surveys of centers, consumers, and local community agencies. Each data source was asked to indicate consumer participation in centers through:

- center information on the composition of their boards and staff, and the importance of consumer participation as an aspect of the center's organizational philosophy;
- consumer assessment of the center's success in involving individuals with disabilities as key members of staff and

management, as well as indicating their own involvement with the center; and

- community-agency assessment of the degree of emphasis their local center seemed to place on consumer participation.

In addition, site visit discussions with center staff, consumers, and community agency staff offered an opportunity to examine more closely the extent and nature of consumer participation in the centers.

Center findings emphasized the importance of consumer participation in center management and decision-making as an integral part of program philosophy. Centers rated the importance of having persons with disabilities control center policy direction and management, establish service priorities, manage center operations, and serve in important staff roles at an average of 4.5 on a five-point scale (see Table VI-1). The community agencies surveyed confirmed the center's reported commitment to consumer participation by also rating all of these aspects as major emphases in their local centers with an average score of 3.9 on the same scales.

Consumers were asked to rate the extent to which the centers had involved persons with disabilities in key staff and management positions. Based on a five-point scale, the mean response was 4.3. In addition, consumers indicated their involvement with providing assistance at centers, either in paid or volunteer positions. Thirty-two percent of the respondents noted that they had helped in some way, including 2% who served on the Board of Directors, 3% who worked as paid staff, 8% who sat on an advisory committee, 7% who assisted in the evaluation of services, and 14% who worked as volunteer staff.

Finally, consumers were asked to describe staff from whom they had received services or had interacted with at the center. While 21% of

Table VI-1

Community Agency and Center Assessment of Center Emphasis on Consumer Participation

Philosophy Component	% of Community Agencies Giving High Rating (4 or 5)* (N = 100)	Mean Rating by Com-Munity Agencies*	Mean Rating by Centers*
Key staff have disabilities	75	4.0	4.3
Disabled manage center operations	67	3.8	3.7
Disabled establish center priorities	64	3.8	4.2
Disabled control policy direction	71	3.9	4.0

*Based on rating scale of 1 (not an emphasis) to 5 (strong emphasis).

Table VI-2

Consumer Participation in the Centers

Type of Participation	Mean # Per Center	Mean % with Disability	Total Across All Centers	% with Disability Across All Centers
Board of Directors	12	49%	1,447	52%
Advisory Board	7	44	890	72
Director			121	62
Staff:				
Administration	2	50	289	54
Direct Service	6	51	702	56
Support	3	40	306	39
Other	2	45	267	47
Total Staff	14	52	1,564	51
Volunteers	14	57	1,675	58

the respondents had worked most closely with a staff member with a similar disability, a larger percent (44%) had contact with someone with a different disability. However, over half (53%) reported that key staff members had no disabilities.

CONSUMER PARTICIPATION ON BOARDS OF DIRECTORS

The size of the Boards of Directors of centers surveyed averaged 12 members, with an average of 49% members with disabilities (see Table VI-2). Fifty-five percent reported that a majority of their board members had disabilities. Twenty-five centers reported having no board members with disabilities, and 18 programs reported that they had no Boards of Directors. Thus, 43 centers reported no consumer representation in independent policy-making positions.

There does not appear to be a consensus in defining the term "consumer" when addressing consumer participation among board members. Some respondents argued that a parent of a person with a disability who uses center services be counted as a "consumer," even if the offspring were an adult. Similarly, a reformed alcoholic might be counted as a member with a disability. The rationale is that these individuals have first-hand experience with a disability and therefore bring a sensitivity to consumer issues without themselves being consumers of center services. Respondents at the other end of the spectrum argue that, to be counted, a board member should have a severe disability and have received services or be receiving services from a center.

The extent of consumer participation in center policy making has been one of the most difficult and controversial measurement issues in the evaluation. While the Congressional mandate simply calls for participation of individuals with disabilities, proponents of the independent living philosophy urged placing an emphasis on consumer control of center policy making, stating in the standards that a majority of board members should be individuals with disabilities. One contention was that consumer control was essential to promoting self-advocacy and would therefore lead to greater center success. Other concerns were raised about whether a majority representation on the board would actually indicate the degree of consumer control of center policies, given the varying roles of boards in policy making and the varying degrees of influence among board members.

Study findings indicate that the composition of a center's Board of Directors was related to other kinds of consumer participation. For example, if there was a majority of board members with disabilities, there was a higher percentage (25% as opposed to 15%) of total consumer involvement in management and staff positions, and a greater likelihood that the center would have a majority of disabled staff (59% as opposed to 37%).

As centers attempted to find the appropriate balance between recruiting board members with disabilities and gaining members with other kinds of expertise, one of the approaches used was the development of an advisory board.

CONSUMER PARTICIPATION ON ADVISORY BOARDS

Seventy-three centers reported having an organized advisory board with an average of seven members, 44% of whom had a disability. Some centers reported having developed advisory boards as a mechanism for involving consumers in the center policy making process. Most often, these were centers that did not have a majority of members with disabilities on their Boards of Directors, primarily those operating within umbrella agencies. Advisory boards in centers with less than a majority of disabled Board of Directors show an average of 57% disabled advisory board members. In contrast, some centers with a disabled majority on the Board of Directors reported recruiting advisory board members who, rather than being consumers, could bring other expertise to their positions. Thus, an average of only 37% of the advisory board members had disabilities among centers with consumer-controlled Boards of Directors.

REPRESENTATION OF PEOPLE WITH DISABILITIES AMONG CENTER STAFF

Over half of the responding centers (52%) reported their executive director as having a disability. On average, centers reported having two administrators and six direct service staff. The majority of staff in both of these categories were disabled individuals (52% and 54%, respectively). In addition, 39% of the support staff employed by the centers were persons with disabilities. Centers reported an average of two other paid staff having disabilities, with close to half (47%) being disabled. Overall, 49% of the centers reported that a majority of their staff had disabilities.

A major source of consumer involvement at some centers was volunteer work. Centers reported receiving assistance from 1,675 volunteers, with an average of 56% disabled per center.

Because Standard 8 states that the centers should employ "qualified disabled individuals," community agencies surveyed were asked to rate the quality of center staff. On a scale of 1 to 5, community agencies rated staff quality in relationship to effectiveness, responsiveness, and cooperativeness. As shown in Table VI-3, from 72-84% of the community agencies gave the centers high ratings of 4 or 5 across the three indicators. Mean scores were all 4.0 or better.

Site visit observations indicate that some centers have struggled with hiring qualified, disabled staff members. Some programs operating under umbrella agencies have not had administrative support for employing persons with disabilities. Some state-operated centers have faced policies that act as obstacles for affirmative action hiring, such as hiring freezes on new employees. Rural centers reported difficulties with having a smaller pool of potential qualified employees with disabilities, as well as the additional difficulty of attracting "outsiders" to potentially less "attractive" communities. Centers also reported that funding uncertainties create work disincentives for a person with disabilities facing loss of subsidized income when entering the competitive job market. Overall, however, the commitment to significant consumer participation in center operations appeared to play an important role in center operations and was often reinforced through staff development activities.

Table VI-3

Community Agency Assessment of Staff Quality

Quality Indicator	% of Agencies Giving High Rating (4 or 5)*	Mean Score*
Effective	72%	4.0
Responsive	75	4.2
Cooperative	84	4.3

*Based on scale of 1 (less) to 5 (more).

SUMMARY

Study findings indicate that there was considerable participation of persons with disabilities in management, decision making, and other staff and volunteer roles, highlighting the fact that centers facilitate consumer representation in key decision making and management positions, as well as in daily center operations. However, at one extreme of the range of respondents, centers existed with few or no consumer representatives. Recruiting and training persons with disabilities who are highly qualified or who have potential for skill development to fill board, executive director, and staff positions remains a critical issue for centers.

VII. DEVELOPMENT OF COMMUNITY OPTIONS FOR INDEPENDENT LIVING

In Section 711(c)(3) of the Rehabilitation Act, Congress has outlined three evaluation requirements relevant to the community-oriented activities of independent living centers. The Act states that the evaluation must describe the extent of:

- "capacity-building activities including collaboration with other agencies and organizations";
- "catalytic activities to promote community awareness, involvement, and assistance"; and
- "outreach efforts and the impact of such efforts."

On the basis of legislative provisions, two evaluation standards were developed to refine the evaluation of center community activities. Standard 4 calls for an assessment of the extent to which centers develop community options for independent living in 12 areas ranging from housing and transportation to increased access to legal services. Standard 7 addresses the centers' community activities such as advocacy and technical assistance, public education, outreach, and establishing an active role in the disabled community.

This description of centers' community activities is based primarily on data collected though the mail surveys sent to all the independent living centers, and to other agencies in the communities of the 36 sample centers. The Center Mail Survey asked questions about center relationships with other organizations, target areas for community activities, proportion of time or resources devoted to developing community options, and center impacts on community options. The Community Agency Survey probed agency relationships with the independent living centers, impacts of contact with centers on the agencies themselves, and assessments of center leadership roles and efforts in expanding community options.

Visits to 36 individual centers also provided valuable information about their community development efforts. While many independent living centers historically have had extensive involvement in promoting community options for independent living -- and have for the most part monitored their levels of activity -- it is difficult to isolate the impacts of these efforts from those of other local actors. For example, because most centers work closely with other agencies, a number of centers were reluctant to "take credit" for improvements in the community even if they clearly contributed to those changes. Some centers in rural areas were concerned about the difficulty of establishing community impact goals in sparsely populated areas, where very few "communities" of significant size exist. However, despite these difficulties, most centers did provide estimates of impacts in a number of different areas, including housing units made accessible, attendants and interpreters added to the local pool, and number of curb cuts made.

This chapter describes the types and levels of community activity, the impacts of these efforts, and the factors leading to center success in expanding community options for independent living.

ACTIVITIES TO PROMOTE COMMUNITY AWARENESS, INVOLVEMENT AND ASSISTANCE

Table VII-1 presents the community development areas that centers reported targeting in their programs. Centers most frequently concentrated their efforts in promoting awareness and acceptance of disabilities, developing more housing options for persons with disabilities, and reducing physical and social barriers in the community. All of these community goals can involve a variety of activities and approaches, depending on the center and its particular local circumstances. For example, some centers work to improve their communities' physical accessibility by conducting surveys to show the level of existing need. Others encourage their disabled members to join city commissions to press local officials for changes, while still others may conduct extensive education or media campaigns, or even hold public demonstrations, if necessary. As Table VII-1 also shows, legal services and health care are the areas that the fewest centers target, largely because other local agencies are usually carrying out these functions.

Table VII-1

Centers' Community Development Target Areas

Target Area	# of Centers Reporting	% of All Centers Reporting
Disability Awareness and Social Acceptance	103	86.6%
Housing Options	100	84.0
Reduction of Barriers (architectural & social)	99	83.2
Transportation Options	85	71.4
Personal Care Availability	84	70.6
Consumer Involvement in Community Activities	83	69.7
Recreation	55	46.2
Communication	53	44.5
Employment Opportunities	44	37.0
Educational Options	43	36.1
Physical and Mental Health Care	31	26.1
Legal Services	17	14.3

All of the independent living centers that responded to the survey reported some involvement in developing community options for independent living. Centers were relatively evenly distributed in their levels of activity, with nearly one-third (31%) devoting over 30% of their time to catalytic activities in the community, and a third allocating less than 20% to community development. On average, centers estimated devoting 25% of their time to such efforts.

Community agencies surveyed by the study stated that centers are working to guarantee equal access to society by individuals with disabilities and that they are meeting the specific independent living needs of the local community (agencies gave centers an average 4.1 rating on a 5-point scale for these two activities). These functions received ratings as high as or higher than most other center areas of involvement and philosophical orientation (see Standard 1, Appendix D).

Nearly three-fourths of the community agencies (74%) also rated independent living centers as "very good" or "outstanding" advocates in their communities. Advocacy is the predominant method used by centers to expand community options for persons with disabilities, involving activities such as providing information about the need for personal care attendant (PCA) funding to state legislators and convincing local officials to increase access to public buildings. Public education is another important tool for promoting community awareness of disabilities. Center activities in this area vary widely, usually involving presentations, brochures, videotapes, media advertising, center-produced newsletters, and extensive staff contact with the public and other service providers. While it is difficult to measure the impact of efforts to increase awareness, according to the community agencies surveyed, these center activities have resulted in educational gains. Thus, 28% of the community agencies responding reported that their staff attitudes towards persons with disabilities had changed, and 26% reported that they had altered their own service approach to disabled individuals as a result of contact with an independent living center.

It also is difficult to measure the impact of center activity on the disabled community as a whole, and to gauge center success in involving more disabled people in community events and activities. Interviews during site visits, however, provided several examples of how centers help create and maintain a sense of community among disabled individuals. To give just one example, a center in a rural area began a recreational program and found that the activity became much more than a swimming class. The program proved to be a vehicle for involving, for the first time, many disabled individuals in the area in a social activity with other disabled people. The center thus used the program as a first step towards wider involvement in the disabled community for persons with disabilities. There were many examples of centers using such methods to help develop and sustain communities in urban, suburban, and rural areas.

CENTER CAPACITY-BUILDING ACTIVITIES AND OUTREACH

A large portion of center activities in developing community options for independent living is directed towards other agencies. The goal is to increase the capacity of other organizations to respond to needs in the local community. Centers also engage in outreach to other service providers and to consumers to publicize the availability of independent living options and to expand the target population for center services.

Table VII-2 presents community agency assessments of the types of relationships they have with independent living centers. While the largest number of agencies (75%) report they refer consumers to a center, the second most frequently reported relationship (60%) is the receipt by the agency of technical assistance and information from the center.

Table VII-2

Community Agency Relationships with Centers

Type of Relationship	% of Agencies Responding
Refer consumers to center	75%
Receive TA	60
Cooperate with center	57
Receive referrals from center	56
Provide TA	49
Coordinate with center	48
Provide funding	24

Table VII-3 (see next page) shows the types of center-reported relationships with a broad range of other community agencies. Of the types of relationships examined, centers most frequently report that they coordinate service delivery with other providers and that they provide information and technical assistance (TA). At least half of the centers coordinate services with VR agencies, primary care facilities, mental health agencies, housing agencies, other disability organizations, transportation services and welfare or social service agencies. Similarly, close to or over half of centers reportedly offer TA or information to all of the above organizations, as well as to other independent living centers, advocacy groups, and businesses or corporations.

Outreach to consumers and other agencies is typically used by new centers, centers that provide rural service delivery, and centers with smaller caseloads. Established centers with large caseloads do not see as great a need for outreach when they are already operating at capacity. In many rural areas, outreach is also the term used to refer to a service delivery approach in which staff travel to consumers' homes

Table VII-3

Independent Living Center Relationships with Community Agencies

	Percentage of Centers Which			
Type of Agency	Coordinate on Services	Coordinate on Advocacy	Provide Information or TA	Receive Information or TA
Other Independent Living Centers	39%	70%	53%	52%
State VR Agency	71	40	58	48
Rehabilitation Facility	51	32	42	26
Primary Care Facility	61	25	50	25
Doctor or Medical Care Provider	41	16	33	31
Mental Retardation/Mental Health Agency	61	44	50	32
Special Education Agency	43	32	43	17
Other Educational Organization	31	30	41	21
Housing Agency	50	38	52	27
Medicaid Agency	31	25	30	28
Advocay Group	41	69	52	40
Lobbying Group	10	45	31	26
Legal Service Organization	32	48	34	40
Disability-Related Organization	54	67	65	44
Agency for Aging	44	37	43	26
Employment Service	29	26	39	21
Transportation Service	55	33	47	20
Social Security Office	28	34	35	44
Welfare or Social Service Agency	55	38	53	28
Private Vendors or Services	41	26	45	33
Business/Corporations	19	20	54	21
Other	8	6	7	7

in order to bridge the distances and physical access barriers commonly found in rural areas. For urban areas, outreach tends to refer to publicity and making contacts with related private and public community agencies to ensure their referral of disabled individuals to the center.

Study findings suggest that outreach activities have been effective in increasing referrals from various sources. Table VII-4 displays the range of sources -- and the rate of utilization -- for referrals to centers.

Table VII-4

How Consumers Heard About Centers

N = 945

Source	% of Consumers	
Friend	23.1	
ILC staff	14.6	
Doctor or health agency staff	16.7	
School	3.3	62.3
VR	13.2	
Other government agencies	7.5	
Media	4.2	
Other	17.4	
Total	100%	

Sixty-two percent of the consumers surveyed reported they learned about centers from community agencies, indicating that other organizations had been informed about centers and that they have some degree of confidence in them. The largest single source of referrals was friends, with 23% of consumers hearing of centers through friendship. As known in the business community, satisfied consumers are a good means of advertisement and they appear to be a fruitful outreach method for independent living centers as well.

The effectiveness of outreach is difficult to assess. Most centers serve a diverse group of disabled consumers and provide them with a wide variety of services. Moreover, the distribution of center consumers by disability approximates the national distribution of disabilities (see Standard 1 in Appendix D). What is not known and has not been examined is how many other individuals are in center communities who also need and could benefit from services, but who are not taking advantage of a center. These individuals might be brought to the center if additional or different kinds of outreach were attempted. However, as long as centers are at their capacity in terms of current resources, such expanded outreach will not likely be matched by an ability on the part of the centers to provide the services needed by these new consumers.

CENTER IMPACTS ON COMMUNITY OPTIONS

Despite the already described difficulties experienced by centers in reporting their community development impacts, there are a number of indicators of success in this area. Table VII-5 summarizes community agency assessments of center effectiveness in expanding community options. There was greatest agreement among community respondents that centers had substantial impacts in the areas of personal care (63%), disability awareness (59%), and transportation (45%). Legal services, employment, and health care were areas where other agencies believed the effects of center activities were least apparent. These were also low priority areas according to the centers' own reports (see Table VII-1). Another measure of center impact on the community is the extent to which other agencies were led to improve their own programs and increase their own involvement in activities for disabled individuals. Nearly 56% of the community agencies, for example, reported that their contact with a center helped them create more options for people with disabilities.

Table VII-5

Community Agency Assessments of Centers' Community Impacts

N = 100

Impact Area	Reported Substantial Center Impact	
	# of Agencies	% of Agencies
Personal Care	61	62.9
Disability Awareness	57	59.4
Transportation	43	44.8
Consumer Involvement	38	40.4
Housing	38	40.0%
Barrier Removal	37	38.5
Communication	36	37.5
Education	28	29.5
Recreation	27	28.1
Health Care	25	26.3
Employment	18	18.9
Legal Services	9	9.6

Overall, centers reported 27,145 positive community impacts across the various outcome areas (see Table VII-6, next page). The highest outcome levels were reported in the two "training" categories: other service providers and health providers trained in the special needs of persons with disabilities represented 23% and 19%, respectively, of the total number of outcomes reported. Adding qualified attendants to the community pool (12%) was the third highest outcome area reported. Indeed, centers reported raising more than $7.5 million in additional funding for attendant, readers, and interpreters.

Because the types of community impacts are so highly varied, it is difficult to compare center efforts across the 18 areas. For example, comparing the number of housing units made accessible to how many service providers were trained gives little indication of the intensity of

Table VII-6

Center-Reported Impacts for Community Activities

Impact Area	% Centers Reporting Impacts[1]	# ($) of Impacts	% of Total Impacts
Educational Agreements	79%	846	3.1%
Attendants	78	3,227	11.9
Recreation Programs	78	976	3.6
Building Accessibility	77	958	3.5
Other Providers Trained	76	6,106	22.5
Housing	75	1,806	6.7
Curb Cuts	74	2,302	8.5
Health Providers Trained	74	5,067	18.7
Job Development	72	1,024	3.8
Communication Devices	68	588	2.2
Parking Spaces	64	1,462	5.4
Transportation	61	979	3.6
Additional Funding for Attendants	58	$7,486,669	---
Educational Resources	57	352	1.3
Interpreters	53	280	1.0
Readers	50	335	1.2
Brailled Information	50	541	2.0
Brailled Elevators	50	296	1.1
Total		27,145	100.0%

[1] Percentage of total number of centers reporting impact area as applicable to their program.

center efforts in these areas precisely because the units of measurement are so different. Comparing the social "value" of the centers developing jobs versus enhancing community accessibility through curb cuts and transportation changes is not within the capability of this study.

Table VII-6 also shows the ratio of centers reporting impacts to centers which stated that the outcome area was applicable to their programs. An average of 66% of the centers recorded outcomes in relevant program areas. Those impact areas with the highest percentage of centers reporting outcome achievement were attendant availability, and recreational programs.

A number of center characteristics were found to be significantly related to community outcomes in bivariate analysis (see Table VII-7). A non-rural setting, presence of a disabled director, a majority of staff members with disabilities, serving a range of disabilities, adherence to the independent living philosophy, a greater community development focus, and procedures for documenting consumer achievement were all significantly related to higher levels of impact for at least some outcome areas.

Statistical analysis also shows that centers which gave priority to specific community development goals were more likely to achieve higher levels of impact in those areas. There were statistically significant relationships between centers that targeted personal care, barrier reduction, recreation, and communication and their achievement of more outcomes in these areas. For example, centers targeting personal care in their community development programs reported adding an average of 49 attendants to the community pool, compared to an average of 17 attendants for those centers which did not focus their community efforts. For more detail about these findings, please see Standard 4 in Appendix D.

Table VII-7

Average Community Outcomes Reported by Different Types of Centers

Center Characteristic	Average Reported Outcomes			
	Housing	Jobs	Attendants	Curb Cuts
1. Adherence to IL Philosophy				
High	30*	21*	50	42
Low	15	13	40	25
2. Percentage of Staff Disabled				
51% +	22	18	39	44*
<50%	22	15	51	21
3. Disabled Director				
Yes	29*	23*	45	37
No	14	11	45	28
4. Rural Service Area				
Yes	12**	15	35*	25
No	25	17	48	35
5. Percentage of Resources for Community Development				
25%+	23	17	51*	38
<25%	20	15	36	25
6. Range of Disabilities Served				
4, 5, or 6 Disabilities	23	15	42	34*
1, 2, or 3 Disabilities	18	25	64	21
7. Documentation of Client Achievement				
Yes	22	15	44	36*
No	20	22	47	16

*Relationship between variables significant at .2 level.

**Relationship between variables significant at .05 level.

The analysis also examined more closely which organizational characteristics were associated with higher levels of center impacts. An outcome measure that combined the two areas of highest center-reported achievement -- training of health and other service providers -- was used in multivariate analysis with a range of several organizational variables. This analysis showed that the following kinds of centers were more likely to achieve high levels of center community impact even when controlling for other major factors: free-standing centers as opposed to those within umbrella agencies; centers with larger agency budgets; centers that had been in operation longer; direct grantees (as opposed to VR subcontractors); centers with more extensive management and monitoring procedures; and those serving a local area rather than an entire state. In addition, centers that placed greater emphasis on independent living philosophy (as defined in Standard 1) had greater community impacts than other centers.

CONCLUSION

The study data show that independent living centers devoted a substantial share of their resources to catalytic activities in the community. On average, centers allocated 25% of their level of effort to such activities, and concentrated primarily on promoting disability awareness, reducing architectural and social barriers, and creating more housing options. According to nearly three-fourths of the other organizations surveyed in their communities, centers were effective advocates for people with disabilities.

Centers also engaged in a number of activities to build the capacity of their communities to respond to the needs of disabled individuals. These capacity-building efforts, as measured by the types and extent of center relationships with other community organizations, were also substantial. Centers were most frequently involved in referral and service coordination relationships and -- according to both center and other agency reports -- often provided technical assistance and information to a wide range of organizations.

Center outreach to consumers and other agencies appeared to be effective. Over 60% of consumers surveyed first heard of an independent living center from another agency, indicating that these other agencies were aware of the options available through a center. In addition, while the effectiveness of outreach is difficult to measure, the range of disabilities among the consumers served by centers reflects the distribution of disabilities in the national population.

Centers experienced some difficulties in reporting the impacts of their community activities. However, an average of 66% of the centers could report outcomes in community development areas applicable to their programs. Community agencies most frequently cited personal care, disability awareness, and transportation as the areas of greatest center community impact. Centers reported the highest levels of achievement in training other providers in the needs of persons with disabilities and in expanding attendant care options.

Statistical bivariate analysis of the factors leading to greater center success in community development shows that more positive outcomes are reported when centers:

- devote more resources to community development;
- specifically target their efforts towards particular areas for community development (especialy true for personal care and reducing architectural barriers);
- agree more strongly with the independent living philosophy and involve more consumers in the daily operations and management of the center;
- operate in non-rural areas;
- serve a wider range of disabilities; and
- use evaluation procedures.

These findings indicate that the overall level of effort in community development and specific targeting of certain impact areas do make a difference in what centers achieve, that consumer involvement is critical for center success as a catalytic force in the community, and that effective management practices lead to a greater ability to show outcome achievement. In addition, these findings show that rural centers are less likely to make an impact on their communities, probably because communities are harder to define and to reach in these areas. Finally, those centers serving a diversity of disabilities appear to be move involved and effective in their community activities.

Multivariate analysis confirmed that philosophy and some management practices (financial and planning) are significantly related to achievement. Regression results also point to some additional conclusions:

- being within an umbrella agency (whether a nonprofit agency or a government agency) may limit a center's community involvement, thereby reducing the likelihood of bringing about community changes;
- greater resources help centers produce more results, suggesting an economy of scale for larger centers;*
- more experienced centers are able to achieve higher levels of impact; and
- concentration of efforts within a smaller geographic area is more effective for bringing about community change.

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*That is, cost per outcome achieved is lower for larger centers. As noted on page 118, cost per consumer served is actually higher for larger centers.

VIII. MANAGEMENT OF CENTERS FOR INDEPENDENT LIVING

This chapter reviews and evaluates the current management practices within the Part B independent living centers. Four types of practice are assessed: (a) program and financial planning; (b) organizational and personnel management, (c) fiscal management, and (d) recordkeeping and evaluation. The concern for center management and reporting procedures responds to the last of the Congressional questions, which asks for "the comparison, when appropriate, of prior year(s) activities with most recent year activity." The four types of practices also correspond directly to the last four of the evaluation standards (Standards 9-12).

PROGRAM AND FINANCIAL PLANNING

Standard 9 asks centers to "establish clear priorities through annual and three-year program and financial planning objectives," which "include, but are not limited to" a number of specific elements, including goals, work plans, specific objectives, service priorities, and budget projections. The center mail survey probed the extent to which centers practiced each of these procedures, and site visits included a review of how they were implemented.

Most centers reported having the necessary planning procedures in place, but often did not use them to influence management and direction of the program. The planning that centers do appears to be principally that which is required of them by potential funding agencies and the grant-writing process. The large majority of centers (82%) engage in formal annual planning procedures, 73% prepare written work plans with timelines for achieving objectives, and 92% report preparing annual service priorities and identifying needs to address in the coming year. Almost all centers (94%) can provide written descriptions of their services and service delivery procedures, and 88% report they have written policies and procedures for board and staff, specifying roles and responsibilities. Such written descriptions vary from brochures and brief descriptions to very elaborate manuals, according to site visit observations.

Planning practices that affect day-to-day management of the center were less in evidence than the basic forms just described. Thus, while annual budget projections are prepared by most centers (98%), few centers (35%) make longer range projections. Center administrators reported during the site visits that such projections were not useful since funding opportunities change so frequently, creating a need to be opportunistic, flexible and able to take advantage of changing funding opportunities whenever and wherever they arise. Similarly, only 59% of centers reported defining specific objectives for the numbers and types of disabilities of individuals to be served, and fewer centers (27%) had developed three-year plans for services and consumers. Many centers also indicated during site visits that the specific objectives which they had articulated were primarily to meet grant requirements, and are not often used as planning tools to shape the management and direction of the centers.

ORGANIZATIONAL AND PERSONNEL MANAGEMENT

Standard 10 states that "The center shall use sound organizational and personnel management practices," and specifies six elements for such procedures. These elements seek to: enhance communication between administration, board, and staff; delineate lines of authority; protect personnel rights; and encourage the ongoing education and training of involved staff.

A large majority of centers report having the procedures outlined by Standard 10 in place. All of the centers maintain written personnel policies and job descriptions, 98% have developed organizational charts, 93% have written affirmative action and equal opportunity policies and conduct annual personnel performance evaluations in writing, and 88% maintain written policies specifying board and staff roles and responsibilities. While 95% of the centers sponsor staff training and development, only 73% do the same for their boards.

Field researchers confirmed that documents required to implement these procedures generally were available, but also noted that many centers remain in flux as the process of organizational growth and operational stabilization proceeds. The personnel practices of centers operating within umbrella agencies, especially within state government contexts, tended to be more formalized, highly developed, and in some cases, even rigid, according to site observations. For example, one state required all vacancies to be filled first from lists of state employees who had been furloughed, second from current employees wanting transfer, and only third from new applicants, making it more difficult to hire disabled staff. Despite the existence of formal personnel procedures, many types of centers experienced conflicts and tensions in providing equal employment and affirmative action opportunities when disabled applicants, who might not have had an extensive employment background, and nondisabled individuals competed for the same job. Finally, although umbrella organizations displayed lower levels of flexibility in hiring and managing personnel, centers operating under umbrella agencies tended to have well-developed systems for staff appraisals and clear lines of authority, in contrast to developing and free-standing centers, which tended to operate on a more informal basis.

FISCAL MANAGEMENT

Standard 11 states that "the center shall practice sound fiscal management," specifying a range of essential procedures. Most centers reported having in place such procedures as: annual budgets that identify funding sources and the allocation of resources across services and activities (96%); a budget monitoring system (97%); procedures for managing cash flow (92%); annual audits by independent accountants (86%); grant development activities (96%); financial information systems that permit the determination of total program cost (97%); and cost by funding source (95%).

Furthermore, the centers appear to be engaging in a broad variety of efforts to develop income outside of grants. A large majority of the centers (73%) had established fee-for-service agreements with other agencies, and a surprisingly large minority (43%) were engaged in business development. This trend is reflected in the fact that 59% of the centers reported that a majority of their funding is obtained through sources other than Part B.

As with the planning activities, however, centers may have somewhat overstated their fiscal management capabilities. Most of the elements reported are the basic systems minimally needed to sustain the organization over time. However, fewer centers reported the ability to use fiscal information in the management of center programs through practices such as analysis of cost per service unit delivered or of cost per consumer (49%).

EVALUATION

Standard 12 states that "the grantee and the centers shall conduct annual self-evaluations and shall maintain records adequate to measure performance" on the Independent Living Center Evaluation Standards, again specifying a number of specific elements where documentation was essential. Most centers reported having systems with these specified procedures in place: maintaining an unduplicated count of disabled individuals served by the center (99%); documenting the types and units of services provided (91%); maintaining consumer intake records (98%), service plans (96%), and progress records (98%); preparing annual evaluation reports that document individual and community outcomes and impacts (75%); and documenting the specific levels of independent living goal achievement by individual consumers (75%). Site visit discussions revealed that in many centers, where individuals receiving only information and referral assistance were not considered consumers, these practices applied only to direct service consumers.

Maintaining individual consumer service and outcome records is critical for assessing performance and indicating service strategies that may improve performance. Eighty-three percent of the centers offering a service were, on average across 18 different service areas, able to provide data on the numbers of consumers provided the service, and 79% could provide data on the units of service delivered. However, these are average figures indicating that a number of centers are unable to provide these data and may require assistance in this area. In addition, the wide diversity in the types of service units reported (nearly 40 different types of service units were identified from the surveys received) makes it difficult to assess the usefulness of center service records for self-evaluation purposes.

Most centers provided consumer outcome data (86% on average across 14 different kinds of individual outcomes). However, these were more often reported as estimates than exact figures from center records. Less than a third of the centers were able to provide exact data directly from records for 10 of the 14 outcomes. The remaining centers provided estimates only. Often this was due to lack of previously established common outcome definitions in the independent living field and thus the inconsistency across centers in how outcomes were measured. Similarly, when 18 different kind of community impacts were probed, between 16% and 24% of the centers were unable to provide estimates of specific types of impacts.

Partly because no reporting requirements have been in place, a common taxonomy of services, consumer descriptors, and outcome measures has not been developed. Standardized practices are also difficult to achieve because of the wide diversity in services delivered and in consumer goals for outcomes that exist in an independent living center (in contrast, for example, to vocational rehabilitation programs focusing primarily on employment outcomes).

Given this diversity in consumers, services and outcomes, it is especially difficult to aggregate and assess data for particular categories when it must be done manually; yet computerization was rare among centers for consumer records (37%) and service records (22%). Computerization was more common for financial records (60%), though still not used by all centers. Centers that had computerized systems clearly seemed to have more planning, fiscal management and evaluation capability. Centers that had computerized their financial information were thus more likely to be able to determine cost per service (70% versus 53% of centers lacking computerized systems), and also more likely to be able to determine cost per consumer (55% versus 40%). Centers with computerized service data were more likely to document consumer goals (89% versus 72%) and issue evaluation reports (92% versus 70%) than those with manual systems.

The more detailed analysis of Standard 11 in Appendix D probes whether management practices varied under different organizational settings. Among the patterns that emerged were that centers were more likely to have stronger fiscal management when: the overall center budget was larger (thus permitting the center to afford computerization or the staf time for such fiscal support activity); when the centers had been operating for a longer period of time (indicating that a more mature level of operational management had been achieved); and when the proportion of total funding from Part B was smaller (indicating perhaps that the center was being held accountable by several different grantors and thus had more demands for financial information and systems placed upon it). The most complete personnel practices were found in centers with a disabled board majority, a larger budget, and a lower proportion of Part B funding. No other patterns of relationship between center management practices and organizational characteristics were noted.

IX. FACTORS INFLUENCING CENTER OPERATIONS AND OUTCOMES

INTRODUCTION

This chapter summarizes the findings of the multivariate analyses that formed a substantial part of the analytic design under which this evaluation was conducted. That design not only emphasized the gathering of information to respond to the Congressional questions concerning the centers' activities and appraising their performance in terms of the evaluation standards, but also sought to understand and explain what factors influenced the successful operation and outcomes of the centers. Decision-makers currently face a number of important policy issues, including:

- What should be the level of funding support for the Part B program? How important is Part B funding in shaping the operations and success of the centers? Should Part B funding be institutionalized as a permanent base of funding support for the centers or should it remain a discretionary grant program?
- What is the appropriate role of the VR agencies in the administration of the program? How has having VR agencies serve as grantee affected centers, compared to funding centers directly?
- How necessary is it that the goals of consumer participation and involvement in the management of the centers be extended to specific goals for a board majority of persons with disabilities? Alternatively, to what extent has the commitment of some centers to consumer participation, which has prompted centers to hire directors and a large proportion of staff from among persons with disabilities, influenced their center's performance?

Findings from the evaluation's analyses should assist policy makers to understand the impacts on program consumers of the various policy choices that might be made.

The analyses supporting these findings are described in detail in Appendix E. In analyzing the impacts of various factors, both bivariate (cross-tabulations) and multivariate (regression) techniques were used.

Underlying the analyses was the basic conceptual model described in Chapter I, which saw outcomes -- whether individual or community -- as the result of three clusters of factors: organizational characteristics, consumer characteristics, and services provided. It was expected that the services provided by centers would be explained to some degree by organizational and consumer characteristics. In fact, however, consumer characteristics were not closely related to the services delivered. While there was a somewhat stronger relationship between organizational characteristics and services, services were very much an independent factor, shaping outcomes in their own right. The lack of a stronger relationship between organizational characteristics and services illustrates the tendency of most centers, as confirmed by the site evaluators' comments, to be evolving toward a common "service model" emphasizing core services and the availability of a broad array of other services. The lack of a relationship between consumer characteristics and services supports the field observation that services were highly individualized, and that service needs varied dramatically across individuals, even within disability categories and demographic groups.

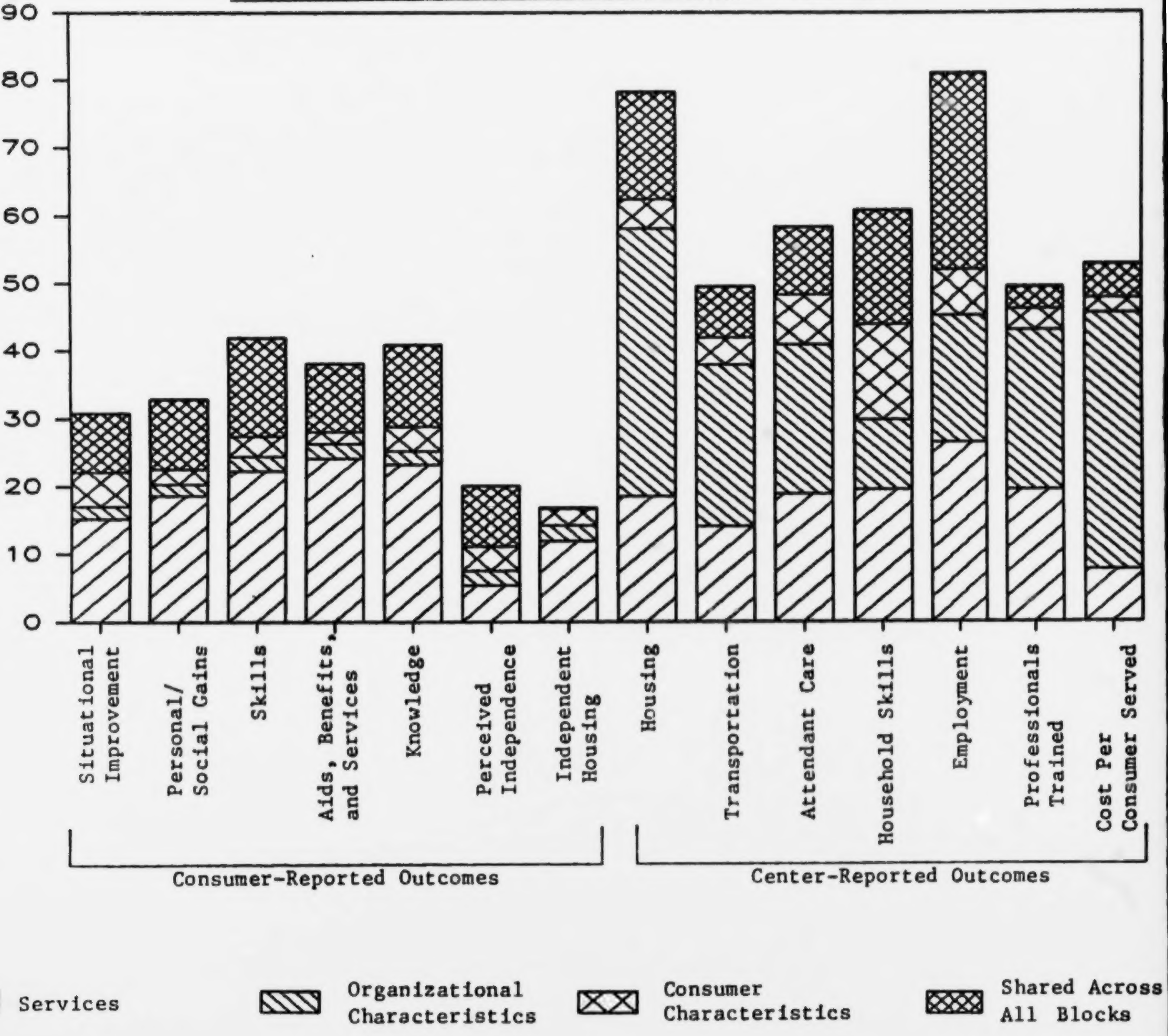
Many factors have a positive effect on some outcome measures, and a negative or neutral effect on others. This pattern reflects the diversity of independent living outcomes (the lack of correlation between the different outcome measures used for most analyses is shown in Appendix E). A consumer who is likely to have a positive outcome in one area (e.g., finding a job or an attendant) is likely to be precisely the client for whom some other outcomes (e.g., obtaining financial assistance or learning health maintenance techniques) would not be relevant.

A second pattern across the analyses is that sometimes different relationships are apparent when organizational and service factors are analyzed with Center Mail Survey data than with the Consumer Mail Survey data. These differences are due in large part to the structure of the study design. For organizational characteristics, the analysis with Consumer Mail Survey data includes only the 36 centers from which consumers were sampled, even though the responses of nearly 1,000 consumers are analyzed. The analysis with Center Mail Survey data involves 121 centers, and thus provides a much larger diversity of center experience for detecting patterns of association between organizational characteristics and outcomes. The outcome data from the Consumer Mail Survey, gathered from all consumers with a common questionnaire, is more uniform than the center outcome data, which are based on centers' varied data collection and reporting systems. Centers reported client outcome data in the aggregate and only indicated whether or not they offered particular services, making it difficult to link services provided to individual client outcomes, while the Consumer Mail Survey collected data on both the services received and outcomes achieved by the same client, thus permitting a much more direct link between services and outcomes.

Figure IX-1 provides an overview of the influence of these various clusters of factors on consumer outcomes as reported both by consumers and by centers. Overall, the services received by consumers accounted for a much larger proportion of the variance in outcomes achieved than either organizational or consumer characteristics. Even center-reported outcomes were substantially influenced by whether or not a service is offered. Organizational factors accounted for a relatively large percentage of the variance for center-reported outcomes but, as expected,

Figure IX-1

Percentage of Variance in Outcomes Explained by Service, Organizational and Consumer Characteristics



showed little relationship to consumer-reported outcomes. Consumer characteristics had relatively little effect overall, although they did appear to exhibit a relatively strong relationship with developing shopping and household skills.

Tables IX-1 through IX-4 summarize the findings of the multivariate analyses, showing the effects of specific characteristics within the organizational, client, and service clusters. A plus (+) sign means that the presence of the factor was associated with a higher level of outcomes. A minus (-) sign means that the presence of the factor was associated with a lower level of outcomes. If there is no sign, then the relationship found by the analysis was not statistically significant and therefore not reported.[1]

While these tables show the effects of certain characteristics on other characteristics -- and the consistency or statistical significance of the relationships -- they do not provide information about the strength of the effects indicated. The magnitude of these factors' influence on each outcome is illustrated graphically in bar charts (Figures IX-2 through IX-15) at the end of this chapter.

WHAT DIFFERENCE DO SERVICES AND SERVICE CHARACTERISTICS MAKE?

Table IX-1 shows the relationships between the types of services consumers received and their reported outcomes. All of the services received had a positive effect in at least one of the outcome areas. The service that most consistently affected outcomes was housing, which was positively associated with all seven of the consumer outcome areas. Advocacy, independent living skills training, peer counseling and equipment services also were generally positively related to outcomes; each of them associated with higher outcomes in four of the seven areas.

With the exception of legal services, none of the services received by consumers was negatively associated with any of the

Table IX-1

Consumer-Reported Outcomes by Services Received and Service Characteristics: Results of Separate and Combined Block Multivariate Analysis[1]

Characteristics	Individual Consumers Who Experienced:						
	More Independent Housing	Improved Life Situation	Personal/ Social Changes	Gains In Skills	Aids, Benefits, Services	Gains In Knowledge	Perceived Gains in Independence
Service Received:							
Information and Referral				+		+	
Advocacy		(+)[a]		+	(+)	(+)	+
ILS Training		+	+	(+)		(+)	
Peer Counseling			(+)	(+)		(+)[a]	+[a]
Other Counseling			+	(+)			+
Legal	+[a]	-	+		(+)		
Housing	+	+	+	(+)	+	(+)	+
Equipment				(+)	(+)	(+)	+
Transportation		(+)	+				(+)
Social/Recreational			(+)	(+)		(+)	
Educational		(+)	+	+			
Vocational		(+)[a]		+[a]		(+)	
Communication			+		(+)		
Personal Assistance				(+)	(+)	(+)	
Electronic					(+)		
Other							(+)
Service Characteristics:							
Frequency of Contact		+	(+)	+	(+)	+	
Personal and Direct Center Contact			+	(+)		+	(+)
Length of Service Period	+	(+)	+				
Long Service Period (4+ years)	-	-[a]	-				-[a]
Case Management	(+)	+	+	+		+	(+)
Staff with Similar Disability	-						
Staff with Different Disability			+			+	+
Consumer Volunteered at Center		+[a]			+	+	

KEY

+ or - = relationship significant at .2 level

(+) or (-) = relationship significant at .05 level or better

a = loses statistical significance when blocks of variables are combined in multivariate analysis consumer-reported outcomes. Consumers receiving legal services were less likely to report situational improvements. Their need for legal assistance perhaps implied greater barriers to success that would account for fewer outcomes.

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[1] In the multivariate analysis, services, consumer characteristics, and organizational characteristics are all used as variables, not merely the variables for which results are reported on this page.

Table IX-1 also shows the relationships between selected service characteristics identified by consumers and their reported outcomes. Case management, which was positively associated with higher outcomes in five of the seven areas, exhibited the most consistent effects of all the service characteristics tested. The frequency of consumer contact with the center and the nature of that contact (i.e., services were received in person rather than by phone) also consistently influenced outcome levels in several areas. A longer service period, working primarily with a staff person that had a different disability, and volunteering at the center made a difference in the number of achievements reported in a total of three areas. However, consumers who worked with centers for an especially long period — four or more years — were less likely to report outcomes in a total of four categories, implying that the benefits of center services may diminish after a certain point (or that these consumers are those individuals least likely ever to achieve an independent lifestyle). Generally, controlling for the effects of other factors, service characteristics provide a powerful explanation for differences in consumer achievement.

Table IX-2 shows the relationship between center-reported outcomes and services offered by the centers. There were no consistent relationships between whether or not a given service was offered and the number of outcomes reported. Each service was positively related to some outcomes and negatively related to others, implying that the mere availability of a service explains very little about the variation in outcomes reported. Note also in Figures IX-9 through IX-15 (at the end of the chapter) that the effect of services offered is quite small in

Table IX-2

Center-Reported Outcomes by Whether or Not a Service is Offered:

Results of Separate and Combined Block Multivariate Analysis[1]

	Total Number of Consumers:					Other Outcomes	
Service Offered	Obtained Housing Modifications	Taught to use Transportation	Acquired Attendants	Taught Household Chores	Obtained Employment	Professionals Trained About Disabilities	Cost Per Consumer
Advocacy	-			(-)	+		
ILS Training					(+)	+	+[a]
Peer Counseling			+[a]		-		
Legal	+	+			(-)		
Professional Counseling	-				+[a]	-[a]	
Other Counseling	+			(-)		(-)	
Housing					+	+[a]	
Equipment			-[a]	-	(-)	(-)	
Transportation		+		+	-		
Recreation	-			+		+	
Educational		-[a]		(-)		+[a]	
Vocational							-
Communication	-	-					
Attendant		+	+	-[a]	-	(-)	
Electronic		+		+[a]	+		+[a]
Family Support	+[a]					(+)	+
I&R	(-)		-		(-)	+	
Other			+	-[a]	(-)		

KEY

+ or - = relationship significant at .2 level

(+) or (-) = relationship significant at .05 level or better

a = loses statistical significance when blocks of variables are combined in multivariate analysis magnitude compared to the direct effect of an individual receiving specific services.

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[1] In the multivariate analysis, services, consumer characteristics, and organizational characteristics are all used as variables, not merely the variables for which results are reported on this page.

WHAT IS THE EFFECT OF FUNDING LEVEL ON CENTER PROGRAMS?

Funding level, and especially its certainty over time, seems to be a critical factor in center success. Centers reported during site visits that funding uncertainty caused major difficulties in attracting and retaining skilled and experienced staff; it also often delayed meaningful implementation of planning, fiscal management and evaluation procedures. Centers expended a great deal of adminstrative effort in securing continuing or new funds for the following year from sources other than federal grants, such as county or state agencies or private foundations. These activities thus distracted centers from broader program development activities and day-to-day management oversight.

Centers with larger budgets tended to be the centers which had been in operation longer, had a lower percentage of Part B funds, were freestanding or nonprofit umbrella agencies rather than VR-administered programs, and had disabled board majorities and staff directors with disabilities. Their service areas were less likely to be entire states or rural areas, and they were less likely to allocate large proportions of center resources to community change rather than to direct service activities. Centers with larger budgets were more likely, however, to express a stronger consumer control philosophy.

Centers with larger budgets also tended to serve a broader range of disabilities than those with smaller budgets. This is partly due to the fact that larger amounts of Part B funds were allocated to programs designed to serve a broader range of consumers. The larger centers also offered a broader array of services and were more likely than other centers to provide independent living skills training, housing, equipment, transportation, educational, vocational, attendant, electronic, and information and referral services.

Center budget size was positively associated with numbers of individuals obtaining housing modifications, learning to do shopping and household chores, and numbers of professionals trained about disabilities. However, centers with larger budgets reported fewer individuals obtaining attendants or employment. Larger budgets were associated with higher costs per consumer, a finding which contradicts the expected economy of scale.

WHAT DIFFERENCE DOES THE PROPORTION OF PART B FUNDING WITHIN A CENTER'S BUDGET MAKE?

Centers with a higher percentage of their funding from Part B tended to be newer centers with smaller annual budgets, operating as a subcontractor to VR, newer, serving rural areas, and allocating a smaller portion of resources to community change. They were less likely to have disabled board majorities or a disabled director or to express philosophies emphasizing consumer control. However, they were equally likely to have staff with disabilities.

The greater the dependence on Part B monies, the higher the likelihood the center served a high proportion of consumers with visual impairments and mental retardation. This suggests that Part B funding may be a key source of funding for those centers that are specializing in serving persons who are blind or developmentally disabled.

As shown in Table IX-3, greater dependence on Part B funding was negatively associated with two of the center-reported outcome measures. Centers with a larger proportion of their funding from Part B tended to report fewer consumers acquiring attendants or obtaining employment. This was consistent with other study findings showing that centers which successfully obtained their funding through a range of different sources tended to be the centers with the most effective management practices and service delivery approaches. Also, given the need to respond to various reporting requirements imposed by other funding sources, they were more likely to collect and report outcome data.

Table IX-3

Outcomes by Center Characteristics and Management Practices:

Results of Separate and Combined Block Multivariate Analysis[1]

Characteristics	Center-Reported Outcomes (N=121[2])							Consumer-Reported Outcomes (N=990[2])						
	Obtained Housing Modifications	Taught to use Transportation	Acquired Attendants	Taught Household Chores	Obtained Employment	Professionals Trained About Disabilities	Cost Per Consumer	More Independent Housing	Improved Life Situation	Personal/ Social Changes	Gains In Skills	Aids, Benefits, Services	Gains In Knowledge	Perceived Gains in Independence
Center Characteristics:														
Free-Standing Agency	$+^{a}$	$-^{a}$		-	+	$+^{a}$								
Total Agency Budget	+	+	-		(-)	$+^{a}$	(+)				$(+)^{a}$	$+^{a}$	$+^{a}$	
Years in Operation						$+^{a}$	(-)		$+^{a}$					+
Part B as % Budget			(-)		(-)			$+^{a}$		+	$+^{a}$			
Community Development as % of Effort									+					
Rural Service Area		$-^{a}$		-			+			-				
Disabled Director		$+^{a}$									$(+)^{a}$	$-^{a}$	$-^{a}$	
Disabled Staff	+			+	(+)				$-^{a}$		-	$-^{a}$		
Direct Grantee			$+^{a}$		+	(+)				$-^{a}$	$-^{a}$			$-^{a}$
Nonprofit Organization									$(+)^{a}$	-	-	$(+)^{a}$	$(-)^{a}$	
Partial State Service Area	$+^{a}$	$-^{a}$			-	+	-							
Percent of Consumers Referral Only	-		$-^{a}$	$-^{a}$	(-)	(-)	(+)			$(-)^{a}$	$-^{a}$	$+^{a}$		
Disabled Board	+	$+^{a}$			$-^{a}$	$-^{a}$			$-^{a}$		$-^{a}$		$(-)^{a}$	
IL Philosophy	(-)	(-)	(-)		(-)	+	-	$+^{a}$			(+)	+	+	(+)
Center Management Practices:														
Defines Specific Service Objectives			-			(+)			$+^{a}$			$(-)^{a}$	$(+)^{a}$	(-)
Determines Average Cost Per Service			-			(+)			$+^{a}$				$+^{a}$	
Documents Consumer Goal Achievement							$+^{a}$				$(+)^{a}$		$+^{a}$	

KEY

+ or - = relationship significant at .2 level

(+) or (-) = relationship significant at .05 level or better

a = loses statistical significance when blocks of variables are combined in multivariate analysis

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[1] In the multivariate analysis, services, consumer characteristics, and organizational characteristics are all used as variables, not merely the variables for which results are reported on this page.

[2] Variance for center-reported outcomes is analyzed across 121 centers. However, since the consumer sample was drawn from only 36 centers, variance for consumer-reported outcomes is analyzed across the 36 centers.

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WHAT DIFFERENCE DOES DIRECT FEDERAL FUNDING MAKE?

While the majority of centers operated as subcontractors to state VR agencies, a substantial number received their funding directly from the federal government. In several of the sites visited, the state VR agency had recently decided (or was currently opting) not to apply for Part B funds, and several centers were becoming direct grantees for the first time. However, most respondent centers that received their Part B funding directly at the time of the survey had always been direct grantees.

Direct grantees responding to the survey tended to receive a larger proportion of their funding from Part B, had been in operation longer, and were more likely to serve principally rural areas than centers subcontracting through a VR agency. They were less likely to have a disabled director or a high proportion of staff members with disabilities. They were also less likely to express philosophies emphasizing consumer control over center operations, but were equally likely to have a disabled majority on their board of directors.

Direct grantee centers were more likely to offer the three core services (independent living skills training, advocacy, and peer counseling). All centers were equally likely to offer the other types of services regardless of whether they were subcontractors or direct grantees.

Centers subcontracting through VR tended to have more formalized and extensive management procedures in place, according to site visit observations, especially if they operated within an umbrella agency. In some cases, the VR agency provided guidance and technical assistance to the center in data collection and record-keeping, and VR often imposed reporting requirements. Since the analysis of the relationship between center characteristics and center-reported outcomes is based on the centers' ability to generate their own reports, centers subcontracting through VR would be expected to report a higher number of outcomes. In fact, in the bivariate analysis, there was a fairly consistent relationship between funding arrangement and outcomes, with VR subcontractors reporting a higher number of outcomes. Once the effects of differences in management practices and services were controlled, funding arrangement was no longer a strong predictor of outcome achievement. However, centers operating as subcontractors to VR had fewer employment outcomes and trained fewer professionals about disabilities than centers receiving their funds directly from the federal program. These findings are consistent with site visit reports that some VR agencies discourage subcontractors from providing employment services lest they duplicate VR's own efforts, and that they tend to emphasize direct consumer services rather than community change activities such as disability awareness training.

WHAT DIFFERENCE DOES CONSUMER CONTROL MAKE?

The evaluation included four primary measures of consumer participation in and control of center operations: (1) presence of a director with a disability, (2) the percentage of board members with disabilities, (3) the percentage of staff with disabilities, (4) and the extent to which centers emphasized consumer-oriented independent living philosophies (as defined in Standard 1). There was generally a positive correlation among these elements. Centers with majorities of individuals with disabilities on their boards were more likely to have disabled directors, a higher percentage of staff with disabilities, and a stronger independent living philosophy emphasis than those with less disabled representatives on the board.

Centers with a higher percentage of disabled board members were more likely than other centers to serve consumers with visual impairments, although other consumer participation measures did not show this effect. This is consistent with site visit observations that some of the agencies specializing in serving consumers with visual impairments, though somewhat more traditional in service philosophy than other independent living centers, do tend to emphasize the involvement of visually impaired individuals on their boards of directors. All four consumer control characteristics are associated with serving fewer consumers who were mentally retarded or mentally ill.

Centers with greater consumer participation, as measured by any of the four indicators above, were more likely to provide peer counseling and information and referral services, and three of the four measures were associated with a greater likelihood of providing attendant services. Centers with greater consumer participation were also likely to report more community impacts such as houses modified, attendants added to the local pool, or accessible vehicles added to local transportation systems.

As shown in Table IX-3, the effects of the consumer control indicators on outcomes were somewhat inconsistent in the multivariate analyses. However, the percentage of staff with disabilities had a more consistent effect on outcomes than the presence of a disabled director or percentage of the board with disabilities. Centers with a larger proportion of disabled staff reported higher numbers of consumers obtaining housing modifications, learning to do shopping and household chores, and obtaining employment, even when controlling for the effects of services and consumer characteristics. The importance of disabled staff at the centers was also confirmed by consumers, who reported higher outcomes when the center staff members with whom they had the most contact had disabilities.

The presence of a disabled director is associated with centers reporting a higher number of consumers learning to use public transportation when the effects of other organizational characteristics are controlled. However, this effect loses statistical significance when controlling for the impacts of service and consumer characteristics. The higher the percentage of board members with disabilities, the higher the reported independent living outcomes in a total of two areas, but the lower the number of individuals obtaining employment and the number of professionals trained by the center in disability awareness.

Centers with a greater emphasis on the various components of independent living philosophy reported fewer consumer outcomes than other centers. Site visit observations suggest that this may be due to less extensive service planning and data reporting procedures. The self-help focus of the independent living philosophy and the emphasis on consumer control of one's own service delivery may reduce the likelihood that the center stresses concrete goal setting and documentation of achievements. The independent living philosophy also stresses providing a broad range of services to all persons with disabilities, which involves serving a wide array of disabilities and needs. It may be that centers that fully embrace this approach have more diverse impacts and fewer outcomes in any one area.

These findings from the Center Mail Survey are somewhat confounded by the fact that the influence of each aspect of consumer participation essentially is reversed in the findings from the consumer-reported data. Thus, consumers reported fewer outcomes when their center had a larger proportion of disabled staff and board members, and higher outcomes when the center emphasized the independent living philosophy. While this may indicate that the independent living philosophy is more critical to the types of outcomes reported by consumers than to the center-reported outcome measures, a more likely explanation of this inconsistency is the small number of centers included in the consumer outcome analysis. Note in Figure IX-1 that the amount of variance in consumer-reported outcomes explained by organizational factors as a whole is extremely small.

In summary, then, it appears that the role of disabled staff members in delivering independent living services may be more important to consumer outcomes than control of center management and policy-making by individuals with disabilities. The independent living philosophy of the center does influence to some degree the staffing patterns, services provided and the service delivery methods used by the center. Once the influence of that philosophy on staffing and service has been controlled, the philosophy in and of itself does not appear to positively affect outcomes. In fact, centers with a greater degree of emphasis on the consumer self-help philosophy actually reported fewer outcomes. While consumer participation is associated with higher outcomes in some areas, there is also evidence that centers with little consumer participation can also have high outcomes.

Thus, it may be that the ideal center structure is one that combines highly qualified management with a strong sensitivity to the needs of disabled individuals and the presence of disabled staff in direct delivery of services. Certainly the site visit observations confirmed the importance of consumer involvement in the centers from the perspectives of staff, consumers, and local community agencies. However, while participation is clearly an essential component of the program, there is no clear evidence that either the presence of a disabled director or disabled majority on the Board of Directors ensures more consumer gains.

WHAT DIFFERENCE DO OTHER ORGANIZATIONAL CHARACTERISTICS MAKE?

One of the issues raised by some center staff and directors was whether it was important for centers to operate on a free-standing basis rather than within umbrella agencies. Concerns were raised about the ability of centers operating within other agencies to be autonomous, ensure effective consumer participation, address community advocacy issues, and meet the needs of the local community when these goals may at times conflict with the priorities of the parent organization.

Study findings supported these concerns and indicated that free-standing centers tended to have a higher percentage of both board members and staff who were persons with disabilities, were much more likely to express a strong consumer participation philosophy, and directed a higher proportion of their efforts to developing independent living options in the local community than centers operating within umbrella agencies. Some other differences also emerged. Compared to centers within an umbrella agency, free-standing centers tended to be those that had been in operation longer, had larger budgets with a smaller proportion of funding from Part B, and served part rather than all of a state. They also tended to serve fewer consumers who were visually impaired, mentally retarded or mentally ill than centers under umbrella agencies. Free-standing centers were more likely to offer peer counseling than other centers, but were less likely to offer independent living skills training, other counseling, equipment, recreational, educational, vocational, communication, and electronic services than other centers.

There were consistent relationships between this aspect of organizational structure and some outcomes, including some relationships that persisted even after the other organizational and service characteristics related to free-standing status were controlled. Free-standing centers reported higher numbers of consumers getting jobs or obtaining housing modifications, and higher numbers of professionals trained in disability awareness than other centers. On the other hand, they reported fewer consumers learning to use public transportation or do shopping and household chores.

In addition to the free-standing or umbrella status of the centers, two other aspects of organizational structure were examined for possible relationships with outcomes: length of time in operation, and whether the center was a nonprofit organization or a government agency. Major findings of these analyses included:

- The longer a center had been in operation the lower its average cost per consumer. Older centers also reported training more professionals about disabilities, and consumers from older centers reported more situational improvements and perceived gains in independence.
- Whether a center was a nonprofit organization or a part of a government agency did not significantly affect any of the center-reported outcomes when controlling for the effects of all other factors, and the influence on consumer-reported outcomes was mixed.

WHAT DIFFERENCE DOES EMPHASIZING COMMUNITY CHANGE OR INFORMATION AND REFERRAL SERVICES MAKE?

As described in Chapter VII, almost all centers devote some of their efforts towards increasing access and community options for people with disabilities. There was speculation that these efforts might detract from the centers' provision of direct services to consumers. On the other hand, others contended that community change activities were seen as essential to meeting the needs of consumers and, in fact, may contribute to increased individual consumer outcomes. Neither perspective is completely supported by the data, since there was no significant relationship between the level of center efforts devoted to community change activities and center-reported outcomes, once the effects of all other factors were controlled. However, there was a positive relationship between community change efforts and the numbers of consumers reporting situational improvements.

Most centers provide information and referral assistance to individuals in the community in addition to direct services to consumers. There was speculation that consumers from centers devoting a large proportion of their efforts towards information and referral rather than direct consumer services would achieve fewer outcomes. To construct a proxy for the level of effort devoted to I & R assistance, centers were asked what proportion of the individuals they served received only I & R services. Those centers with a high proportion of I & R consumers did report significantly fewer direct service outcomes than other centers. It appears, then, that greater emphasis on I & R services may detract from consumer achievement. However, this finding probably also indicates that centers are less likely to track and record the outcome achievements of I & R consumers. Centers with a high proportion of I & R consumers were also more likely to have a higher average cost per direct service consumer.

WHAT DIFFERENCE DO GOOD MANAGEMENT PRACTICES MAKE?

Study findings do not indicate consistent relationships between management practices and outcomes when controlling for the effects of other factors. Such practices may have an indirect impact on outcomes through their influence on service mix, service delivery approaches, or consumers served. However, once the effects of these consumer and service aspects were controlled in the analysis, few differences in outcomes remained that could be attributed to management procedures alone.

WHAT DIFFERENCE DOES THE GEOGRAPHIC FOCUS OF A CENTER MAKE?

Centers serving their entire state, rather than just part of the state, were more likely to be nonprofit agencies or operating under a non-profit umbrella agency than to be governmental agencies. They also tended to allocate a larger proportion of their resources to community change than centers with a smaller service area. They were more likely to have a disabled director, but otherwise were no different from other centers in their degree of consumer control. Centers serving an entire state were more likely than other centers to offer advocacy, housing, and attendant services, and less likely to offer professional counseling, electronic, family support, and I & R services. They tended to serve a smaller proportion of the visually impaired, but otherwise had caseloads similar to those of other centers. Once the effect of these factors were controlled, the relationships between geographical service area and outcomes were inconsistent across outcome areas.

Those centers serving exclusively rural areas were more likely than other centers to have smaller budgets with higher proportions of Part B funding, and to receive federal funding directly. They were equally likely to involve consumers in center operations and to allocate resources to community change and information and referral efforts. Rural centers tended not to specialize in serving particular types of disabilities, but did tend to offer a smaller range of services than other centers. They were likely to have a higher cost per consumer and reported fewer consumers learning to use public transportation or do household chores than other centers. Rural service delivery failed to be positively associated with any of the outcomes areas reported by either centers or consumers. This finding is consistent with center reports during site visits that overall, centers serving rural disabled populations confront more difficult service problems than other centers.

WHAT DIFFERENCE DO CONSUMER CHARACTERISTICS MAKE?

As illustrated in Figure IX-1 earlier, on the whole consumer characteristics exhibit a very small effect on outcomes relative to the effects shown by services and organizational characteristics. Consumer characteristics made the greatest difference in situational improvements (positive change in housing, income, employment, education, or transportation). Figure IX-3 at the end of the chapter provides a closer look at the significant consumer characteristics affecting situational improvements. The factor with the greatest influence on this type of outcome was age; younger consumers were much more likely than older consumers to improve their life situation. Consumers living in supervised settings when they first contacted the center also were more likely to achieve improvements. Individuals with severe disabilities and visual impairments were less likely to report situational improvements.

Table IX-4 shows the relationships between each of the consumer characteristics and all consumer-reported outcomes. Several characteristics exhibited consistent effects on this range of outcomes:

- consumers who were currently or had previously been VR clients were more likely to achieve outcomes than those who had never been served by VR;
- consumers who lived in a supervised setting when they first contacted the center were more likely to report gains than those living on their own in the community; and
- consumers for whom another individual (e.g., parent) completed the mail survey were less likely to be reported as achieving outcomes than those completing the survey themselves.

SUMMARY

The most significant factors influencing consumers' success were the characteristics of services received: the overall amount of service, the consumer's personal and continued contact with the center

Table IX-6

Consumer-Reported Outcomes by Consumer Characteristics: Results of Separate and Combined Block Multivariate Analysis[1]

Characteristics	Individual Consumers Who Experienced:						
	More Independent Housing	Improved Life Situation	Personal/ Social Changes	Gains In Skills	Aids, Benefits, Services	Gains In Knowledge	Perceived Gains in Independence
Consumer Characteristics							
Past Work History						-	
Age		(-)	-				
Sex-Female				+			
Minority/Ethnic Group Member							
Time Since Onset of Disability			+^{a}		+^{a}		
Living in Supervised Setting	(+)	(+)	(+)^{a}	(+)	+	(+)^{a}	+^{a}
Living with Parent(s)	+	(+)^{a}		(+)		+	
VR Client		+	+	+	+	+	+
Someone Else Completed Survey	-	-	(-)	(-)	(-)	(-)	
Goal of Improving versus Maintaining	-			(+)^{a}		(+)^{a}	
Presence of Disability:							
Severity of Disability	-	-			(+)^{a}		
Visual Impairment	-	-	+^{a}		+	+^{a}	-
Hearing Impairment							
Mental Illness				+^{a}			(-)
Mental Retardation	-	-^{a}	+	-	(-)^{a}	-	
Other			+			+	

KEY

+ or -	=	relationship significant at .2 level
(+) or (-)	=	relationship significant at .05 level or better
a	=	loses statistical significance when blocks of variables are combined in multivariate analysis

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[1] In the multivariate analysis, services, consumer characteristics, and organizational characteristics are all used as variables, not merely the variables for which results are reported on this page.

over time, the use of central case managers, and the provision of peer role models to consumers through contact with disabled staff. The centers that reported the highest outcomes were those with the highest percentage of staff with disabilities, the highest percentage of funding from nonfederal sources, and those that received their funding directly from the federal government. The consumers who reported the highest outcomes tended to be younger, had disabilities other than mental retardation, were (or had previously been) VR clients, and lived in supervised settings.

Figure IX-2

Significant Factors Affecting Consumer-Reported Housing Independence Gains

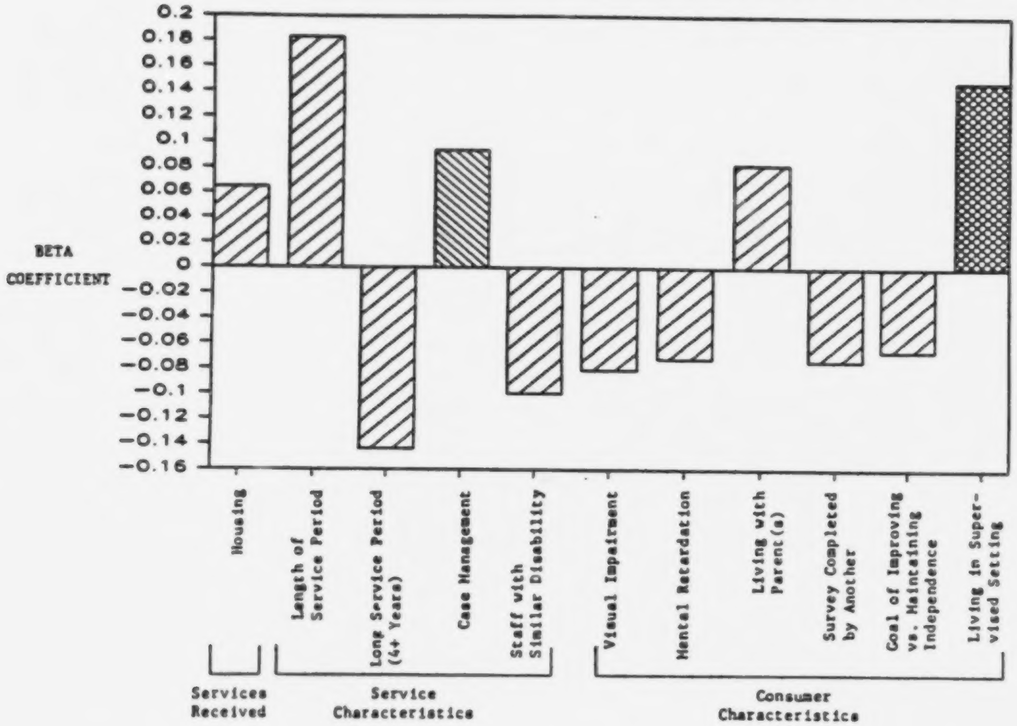
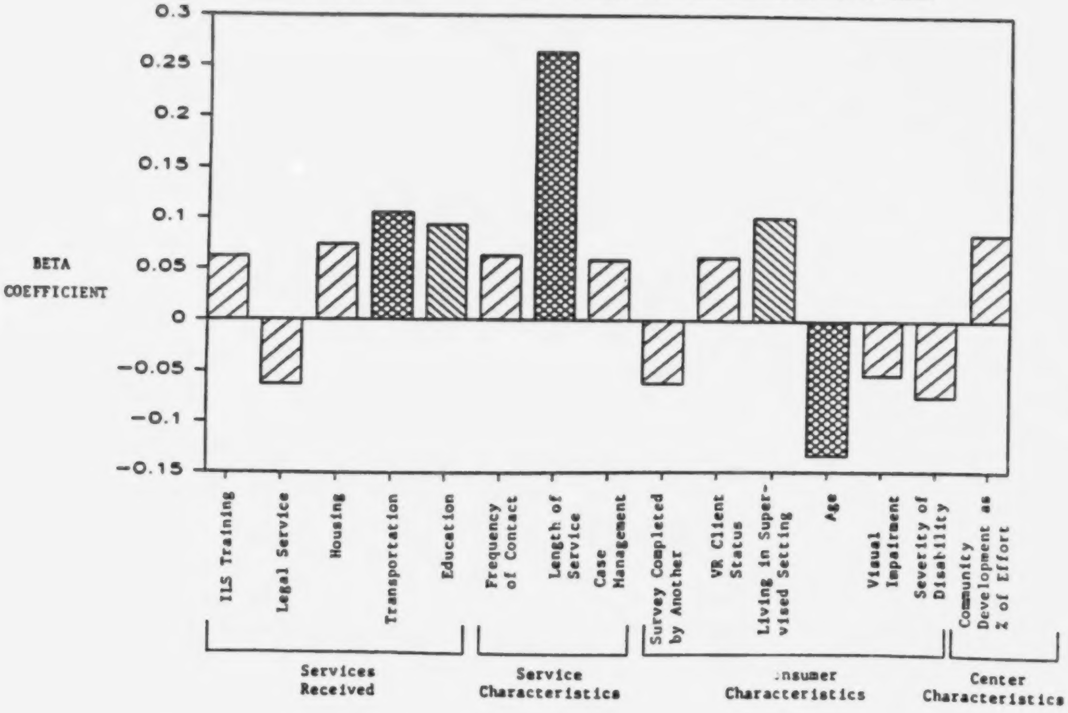


Figure IX-3

Significant Factors Affecting Consumer-Reported Situational Improvements



Level of significance when controlling for service, consumer, and organizational factors:

▨ SIG .20 ▧ SIG .05 ▩ SIG .01

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Figure IX-4

Significant Factors Affecting Personal/Social Change

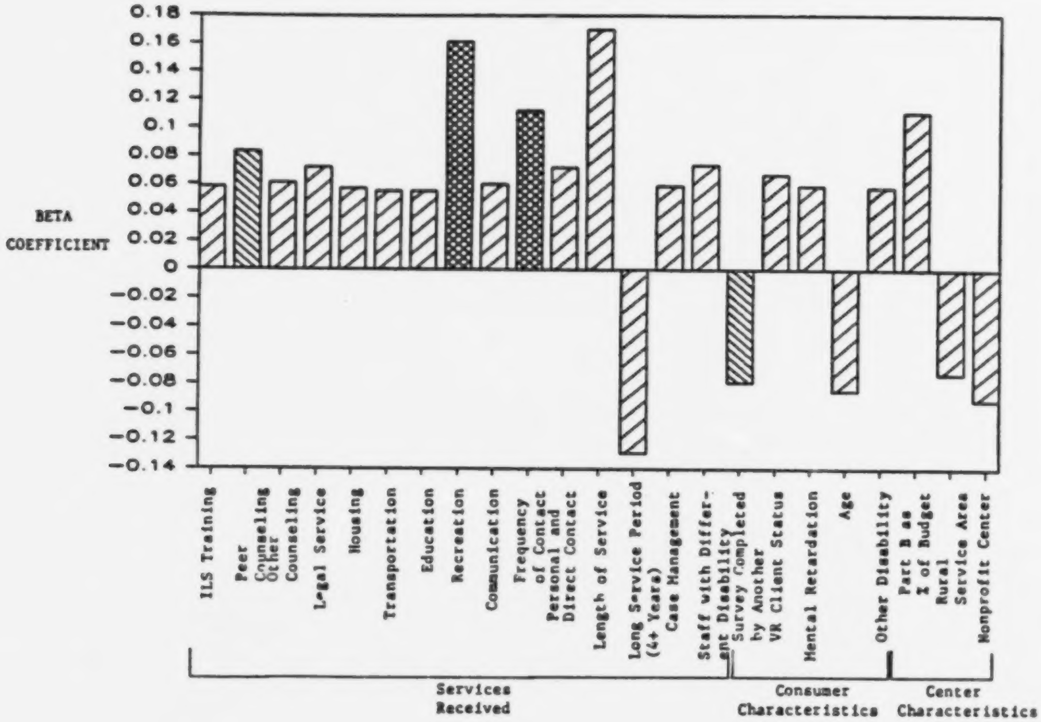
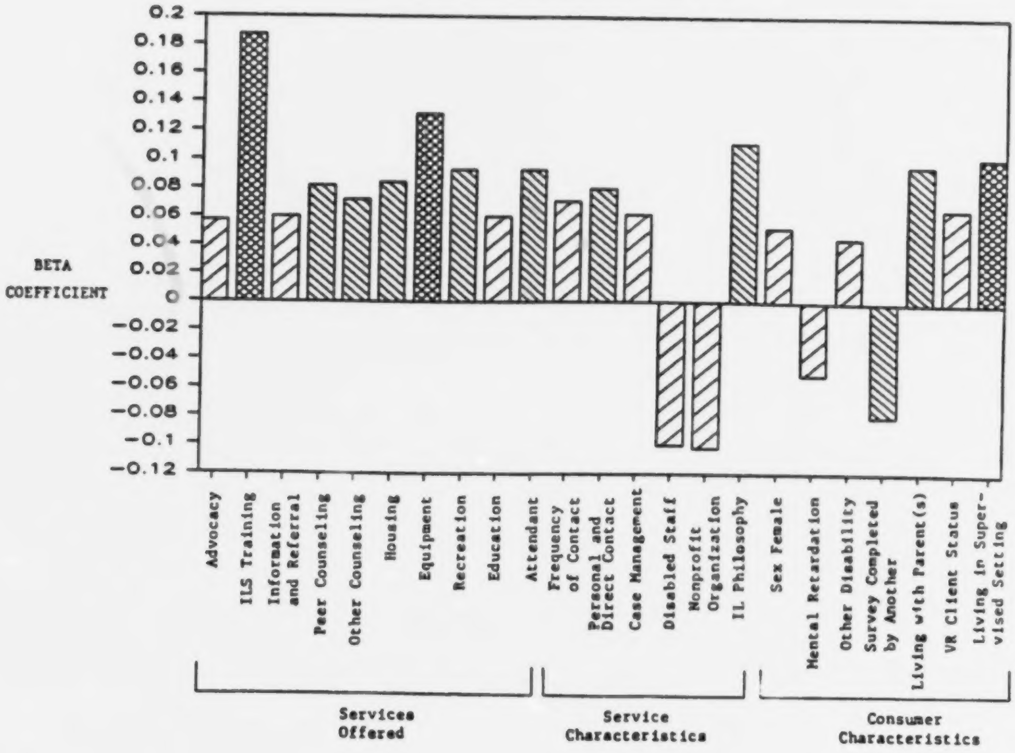


Figure IX-5

Significant Factors Affecting IL Skills



Level of significance when controlling for service, consumer, and organizational factors:

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Figure IX-6

Significant Factors Affecting Consumer-Reported Acquisition of Adaptive Aids, Benefits, Services

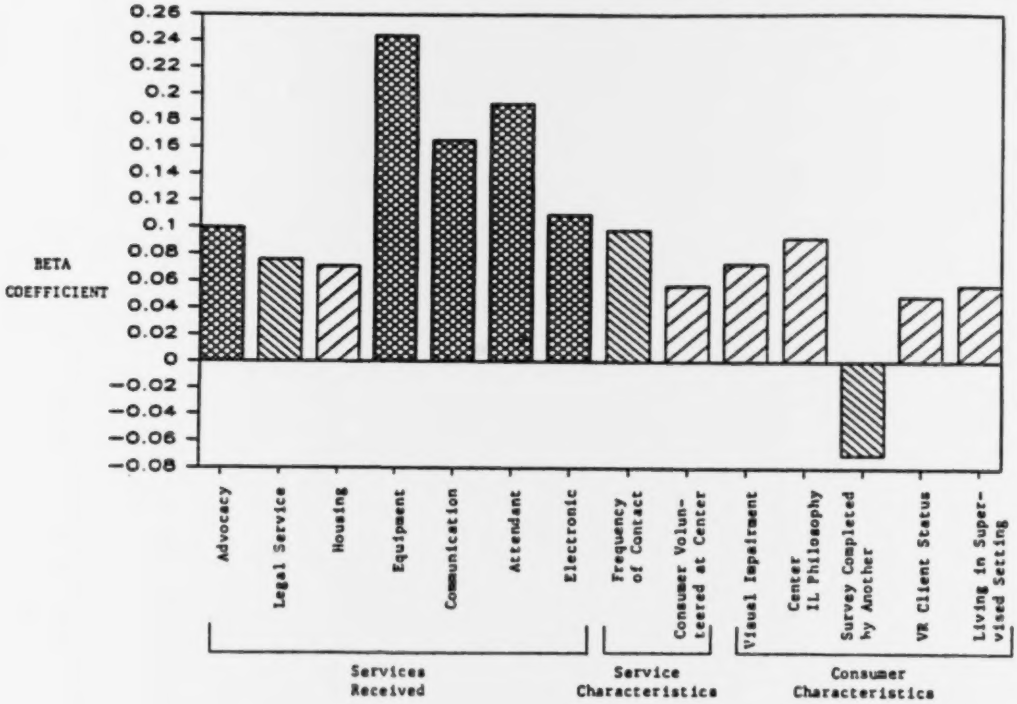
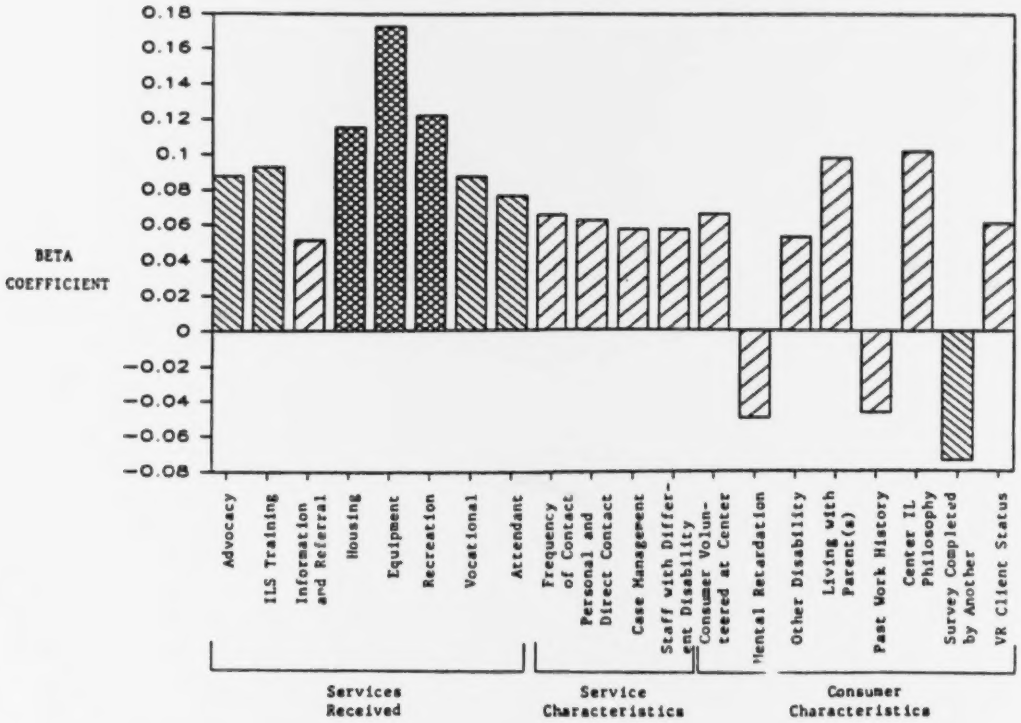


Figure IX-7

Significant Factors Affecting Consumer-Reported Knowledge Gains



Level of significance when controlling for service, consumer, and organizational factors:

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Figure IX-8

Significant Factors Affecting Consumer-Reported Gains in Independence

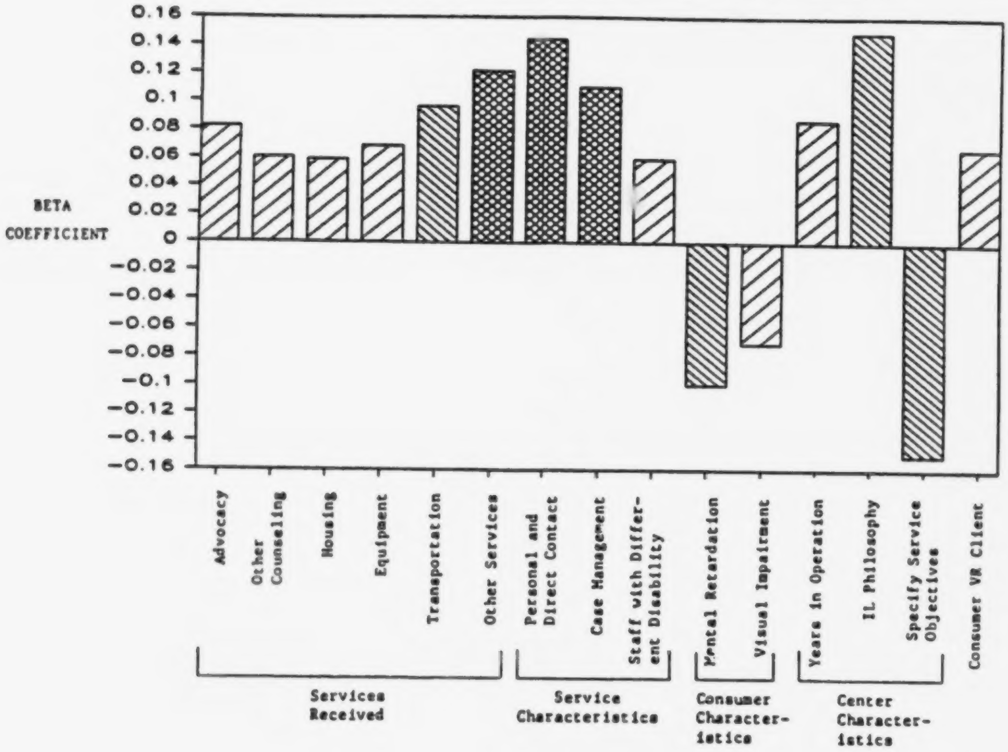
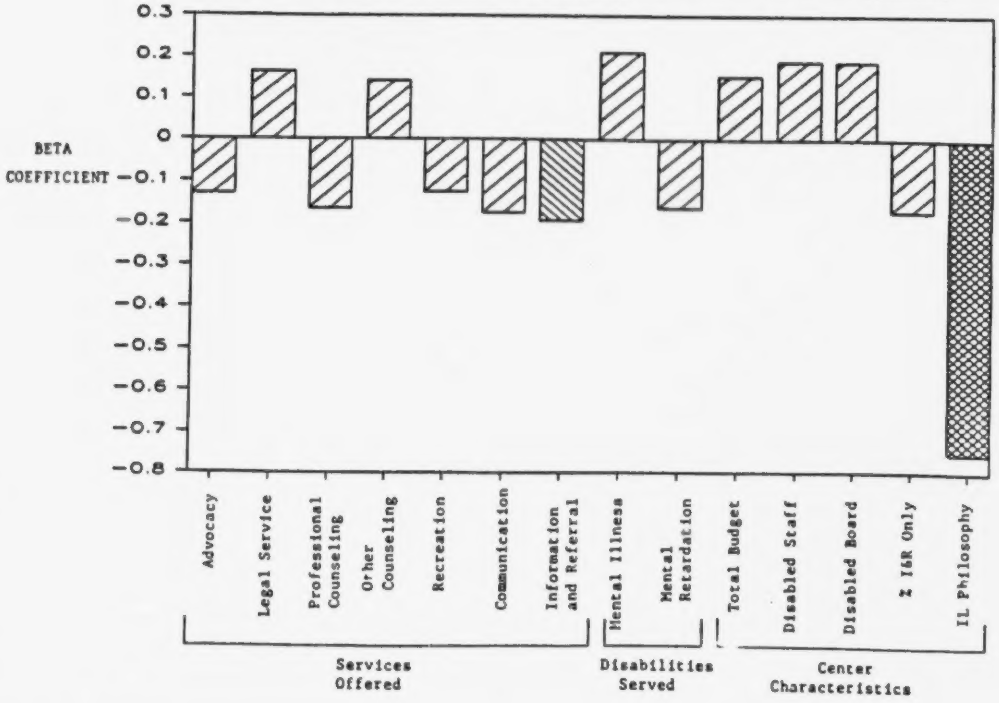


Figure IX-9

Significant Factors Affecting Center-Reported Housing Modification Outcomes



Level of significance when controlling for service, consumer, and organizational factors:

▨ SIG .20 ▧ SIG .05 ▩ SIG .01

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Figure IX-10

Significant Factors Affecting Center-Reported Transportation Outcomes

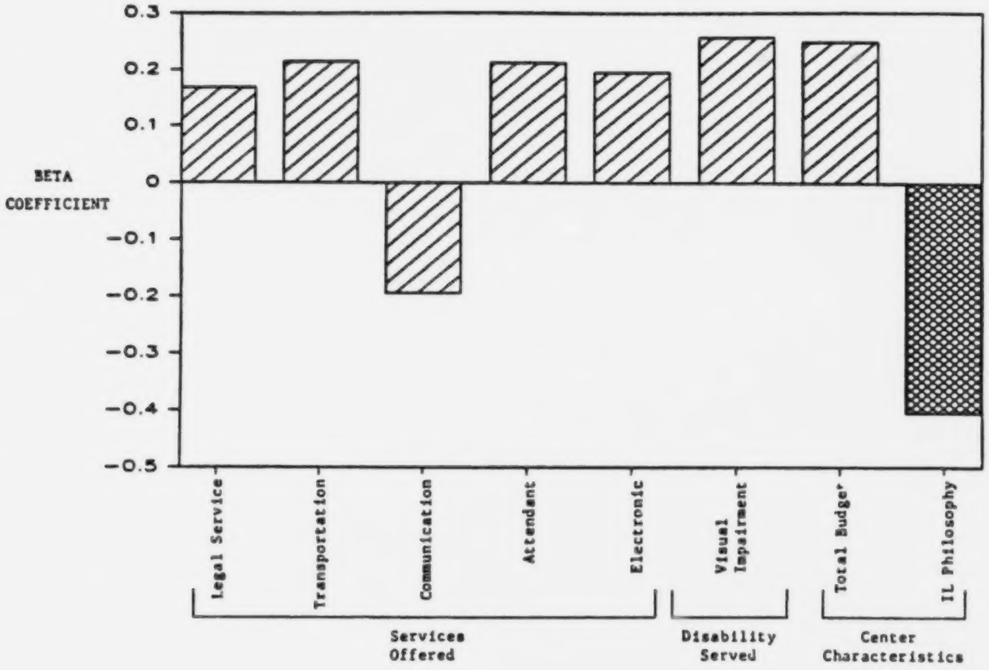
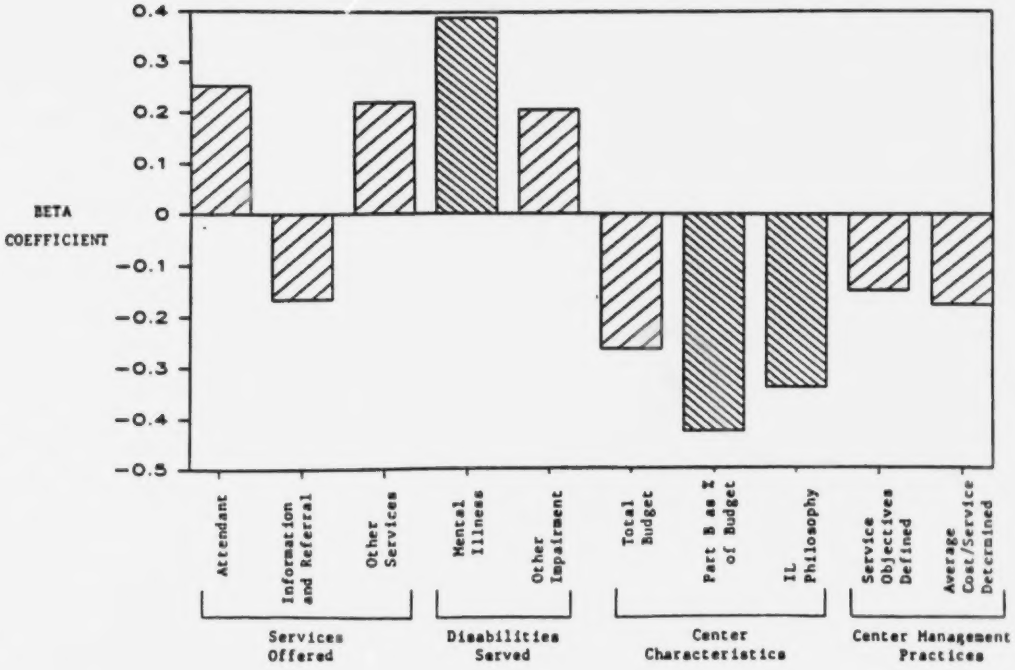


Figure IX-11

Significant Factors Affecting Center-Reported Attendant Care Outcomes



Level of significance when controlling for service, consumer, and organizational factors:

▨ SIG .20 ▧ SIG .05 ▩ SIG .01

Figure IX-12

Significant Factors Affecting Center-Reported Shopping/Household Chores Outcomes

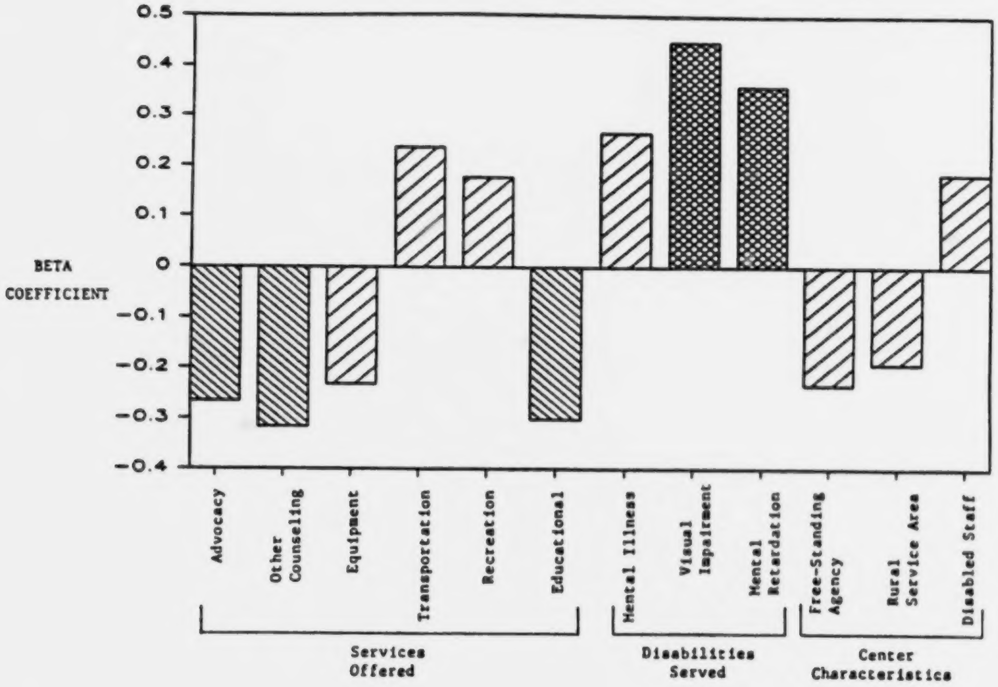
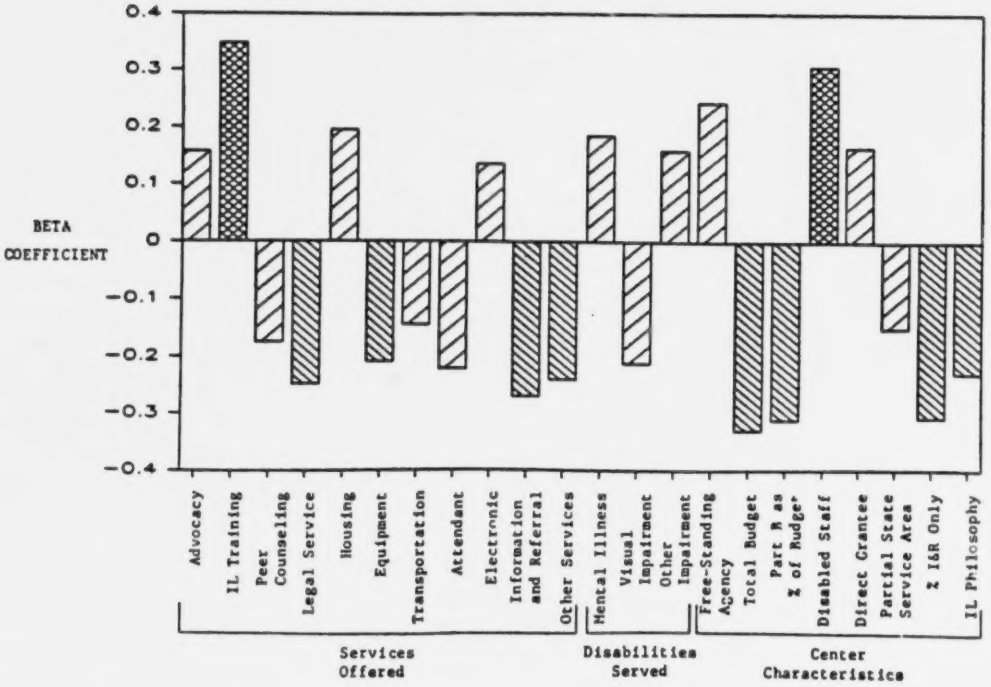


Figure IX-13

Significant Factors Affecting Center-Reported Employment Outcomes



Level of significance when controlling for service, consumer, and organizational factors:

▨ SIG .20 ▧ SIG .05 ▦ SIG .01

Figure IX-14

Significant Factors Affecting Professionals Trained

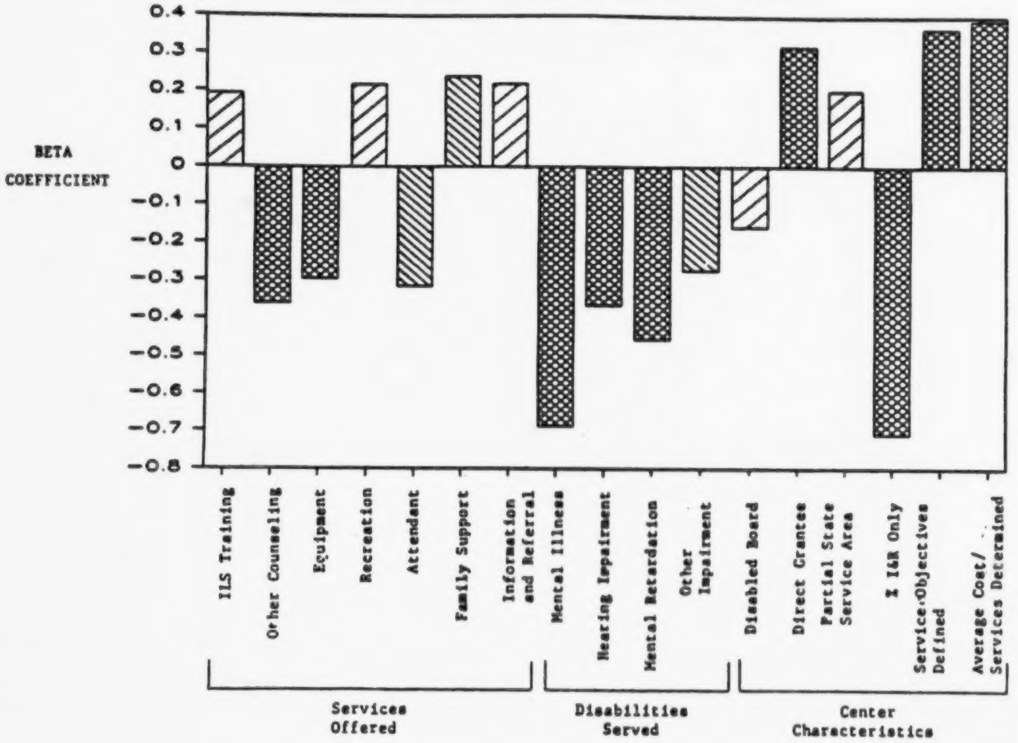
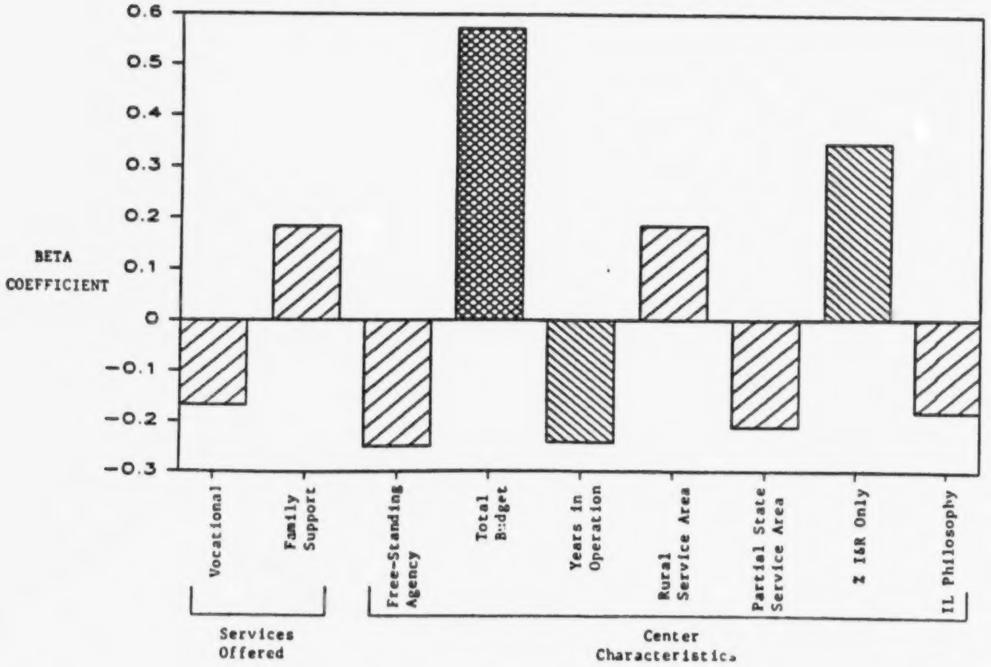


Figure IX-15

Sigirificant Factors Affecting Center-Reported Cost/Consumer



Level of significance when controlling for service, consumer, and organizational factors:

▨ SIG .20 ▧ SIG .05 ▩ SIG .01

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FOOTNOTE

[1] It should be emphasized that Tables IX-1 through IX-4 are reporting multivariate analytic results, which show each factor's association with an outcome when controlling for all other factors. Thus, it is possible that a pattern which is apparent when looking at only two variables may no longer be significant when the effects of other variables are controlled. To draw on a common example from vocational rehabilitation, looking only at the age of a consumer and whether that consumer found a job, one might conclude that it is easier to place older people in jobs. However, controlling for past work history, the relationship may reverse, and one may find that it is more difficult to find jobs for older people.

Tables IX-1 through IX-4 indicate signs only if the factor or variable is statistically significant in analyses conducted with conceptually similar variables (i.e., variables within the services, organizational characteristics, or consumer characteristics cluster) or in the analyses conducted with all three clusters of variables. These procedures are explained at greater length in Appendix E.

When reviewing center outcome data, the following interpretations are appropriate:

- a + sign for an organizational characteristic means that the presence of this organizational factor -- or of a higher level of the factor -- is associated with a higher level of reported aggregated outcomes per 100 clients, controlling for other factors;
- a + sign for a service variable means that if this type of service is offered at all within the overall service package available to consumers at a center (regardless of how many consumers are provided the service), the level of reported aggregated outcomes per 100 consumers will be higher, controlling for other factors;
- a + sign for a consumer characteristic means that as the percentage of consumers with this characteristic increases, the level of reported aggregated outcomes per 100 consumers will be higher, controlling for other factors.

When reviewing consumer outcome data, the following interpretations are appropriate:

- a + sign for an organizational characteristic means that the presence of this organizational factor or a higher level of this characteristic at the center where the consumer is served will increase the number or level of outcomes for a consumer, controlling for other factors;

- a + sign for a service variable means that receipt of this service (regardless of the total amount of the service received) or the experience of this type of service process, increases the number or level of outcomes for that consumer, controlling for other factors;

- a + sign for a consumer characteristic means that if a consumer has this particular characteristic or a higher level of this characteristic, that consumer will have a higher number or level of outcomes, controlling for other factors.

X. PROGRAM MANAGEMENT ISSUES

Many comments and recommendations came forth concerning improvements in the Centers for Independent Living Program overall in the course of interviews with administrators and staff at 40 sites, the center and consumer mail surveys and ongoing review of the evaluation effort by both the national advisory panel and the National Council on the Handicapped. Comments focused on the overall operations of the program, the utility of the evaluation standards being developed, and other aspects of program management. This chapter summarizes and synthesizes those comments and suggestions. The recommendations are organized according to the following topics: (1) the implementation of program-wide guidelines and associated reporting requirements, including refinement in federal policies concerning acceptable project organization, services and outcomes; (2) the need for technical assistance to facilitate accomplishment of project goals; and (3) possible revisions in and future uses of the evaluation standards.

PROGRAM GUIDELINES AND REPORTING REQUIREMENTS

The discussions with national review groups and with independent living center administrators make it clear that there are some major policy issues which remain unresolved. The lack of resolution is not necessarily bad, but it is clear that when different actors are brought together for discussions about independent living at the national level, the issues continue to emerge and be debated. A determination needs to be made about whether the federal program should assert leadership on any of the issues, or whether to continue allowing local discretion within the federally-assisted program. The following issues need consideration:

- whether to define a particular "model" for the Centers for Independent Living Program and focus funding, guidelines, and policy toward that model;
- whether to require that centers serve a broad array of disabilities, as now specified in the standards, or whether to fund some centers that focus only on a particular disability group or a narrow range of disabilities;
- whether to require that centers ensure maximum consumer participation by giving preference to disabled individuals as board members and staff, or whether to allow the current inconsistency in degree of consumer participation;
- whether to specify a given level of consumer involvement, such as the current direction in the evaluation standards that Boards of Directors should have a majority of disabled members, or whether to allow state and local discretion in establishing acceptable levels;
- whether to specify a minimum set of services to be offered by all centers, such as those currently included in the evaluation standards;
- whether to suggest or set priorities among the kinds of disabled individuals to be served by a center, given that resources are likely to remain limited and insufficient for serving all those who might need services. (Should centers focus on the most severely disabled, those at risk of institutionalization or trying to deinstitutionalize, those for whom independent living assistance may supplement vocational rehabilitation services, the young transitioning from special education, or other

groups? Should centers be serving the elderly, members of the disabled individual's family, those only temporarily disabled or with very moderate impairments?); and

- whether to create guidelines for definitions of services and outcomes so that centers use a common language in describing their activities and accomplishments.

The current pattern of great flexibility and diverse historic evolution in different states has yielded an array of approaches to independent living service delivery. Most seem to be working, though some work better than others -- depending on the definition of "success" used. A common service model is evolving, according to the evaluation findings, yet that evolution is much too slow in the perspective of some program leaders and advocates.

If RSA takes a more active role in shaping the program, it will be important to determine to what extent these priorities should be reinforced by reducing or eliminating funding to centers which do not reflect the thrust of these policies, and over what time frame such a shift in emphasis would take place. (Many of the centers studied would be able to achieve the existing standards given an appropriate transition period.)

In addition, it is very clear that independent living centers have not had basic "models" and definitions of how to collect and record data on services, consumers, and outcomes. As a result, each center has had to create its own systems, an expensive and redundant development effort not well-suited to producing information systems that meet management needs and outside accountability demands. In some cases, centers adopt wholesale systems from umbrella agencies. Where the umbrella is a VR agency, there may be some comparability in data across centers. But for the most part, the information available across individual centers is not comparable.

Many centers expressed a desire for more common definitions and measurements for consumer characteristics, types of services and service units, and consumer and community outcomes. They similarly expressed an interest in gaining access to information systems used successfully by other centers, systems for managing cash flow and billings to agencies paying fees for services, and models for consumer service planning or for conducting self-evaluations. Self-evaluations in the absence of comparative performance information from other similar centers are less likely to lead to discoveries of how to improve activities and outcomes.

This interest was not generally a call for federally-promulgated reporting and administrative requirements (though some centers apparently would not object if reasonable commitments to ongoing funding accompanied such requirements). Rather, many centers expressed interest in adopting data collection and reporting conventions on a voluntary basis if such models and conventions were developed. The vehicle for development of such recommended models might be a federal agency (e.g., NCH, RSA, or NIHR) or an association (e.g., NCIL, NRILN, or CARF). An accreditation process, similar to that which was used to improve rehabilitation facilities in the mid-1970s, perhaps might be used. Such a process would emphasize standards development and evaluation by peers, with the goal of helping the program improve its operations.

Finally, a recurrent theme in centers across the country was that funding resources were small relative to the need and demand for services. At the same time, centers viewed federal funding as very unstable and uncertain. It was noted earlier that long-term planning was generally considered infeasible, with centers exploiting any opportunities that might come along for funding. Even personnel management was reported to be affected. Such funding uncertainty is not likely to be easily resolved in the current context of overall federal fiscal uncertainty, but the evaluation must at least acknowledges that this was reported by centers to be an obstacle in the path of improved center management.

TECHNICAL ASSISTANCE, LINKAGES AND OUTREACH

A number of centers expressed the need for technical assistance and other types of support to help them improve their operations, increase their effectiveness in working with other public and private organizations on removing barriers to independent living, and increase their effectiveness in assisting individuals to achieve their independent living goals. Some technical assistance is already being secured by some centers with the help of local resources. Private vendors offering computer software uniquely tailored to the needs of center management and created for use with affordable microcomputers are beginning to enter this program field.

In the absence of strict federal guidelines, state-level grantees have had great flexibility in determining how funds will be used. While in a few cases state VR agencies operated their own programs, generally the funds were subcontracted to local centers. There was tremendous diversity among states visited in terms of criteria for selecting these subcontractors and for programmatic or reporting requirements placed on them. In some states, fierce debates have arisen between state VR and consumer advocates over the extent of consumer participation or control that should be required, over state-mandated reporting requirements, or simply over the degree of autonomy the centers should have and the appropriate role for VR. In other states, VR and the centers have complementary and close working relationships. One model that seemed particularly effective was that in which VR allowed the center greater flexibility in the services it delivered and in its community advocacy role, but imposed standard reporting requirements and sound management practices as a condition of funding, and provided technical assistance to the center to help it comply.

While this flexibility and diversity may be advantageous for encouraging centers to respond to the needs of their own local communities, in the current environment, few mechanisms exist for states and centers to share information and learn from each others' experience. It may be an appropriate federal role to provide assistance to Part B grantees in developing a common set of conventions for measuring services and outcomes and sharing performance data, even if deciding against providing stronger direction for the program.

INDEPENDENT LIVING CENTER EVALUATION STANDARDS

Most center directors interviewed in the site visits supported the notion of national evaluation standards as a management tool, and welcomed the evaluation standards developed as part of this study and promulgated by the National Council on the Handicapped. A number of centers reported revising their internal reporting systems and processes to achieve greater consistency with these standards. In addition, some state VR agencies -- on their own initiative -- have begun exploring the utility of the evaluation standards as a tool for assessing funding applications and center performance.

The information collected for the national evaluation of the Centers for Independent Living Program was designed to address each of the elements contained in the independent living evaluation standards and serves as a baseline for use by RSA in tracking the future progress of the program. It should also assist centers in their individual self-evaluation activities. If the evaluation standards continue to be used by RSA over time, they will facilitate for Congress "comparison, when appropriate, of activities in prior years with activities in the most recent year," which proved infeasible in the current national evaluation. Finally, these standards constitute a framework for program guidelines which many center directors felt would help them improve their operations in serving persons with disabilities.

However, prior to implementation, refinement of the evaluation standards is needed. Several areas of further work were identified during the course of the evaluation:

- While the evaluation standards for the first time spell out the range of consumer and community outcomes that centers should monitor and the range of services to be offered, the actual monitoring of services and outcomes requires further delineation of specific measures (e.g., the units of services, the way in which outcomes of a given type should be measured). These measurement formats need not necessarily be part of the evaluation standards, but some recommended format for such measures needs to be developed;
- A number of evaluation standards list basic and important management systems (Standards 9 through 12) which centers should have in place. The systems listed are generally unassailable, and a center lacking such systems should appropriately be provided assistance. In addition, the quality and effectiveness of alternative forms for those systems can vary dramatically. Similarly, other aspects of center operations, such as extent of consumer participation, cannot be easily assessed simply by examining center characteristics such as percentage of board members with a disability. In these instances, implementation of the evaluation standards would be enhanced by a more in-depth site review permitting assessment of the

quality of systems in place, and by the specification of some "ideal models" or examples for emulation drawn from the best practices of existing centers. A simple direction that centers undergo such intensive site reviews at least once every three or four years, whether by their state VR agency or by some other group, might be a workable approach.

- A number of evaluation standards (e.g. those specifying that centers serve a broad array of disabilities, that a broad array of services be offered, or those specifying substantial consumer participation) are not currently being met by some of the centers that receive Part B funds. Where the national evaluation standards do not conform to RSA funding policy, either the policy or the standards should be changed, with an adequate transition period to allow these centers to come into compliance.

The extensive site visits to 40 centers, and the evaluation findings for the data submitted by consumers and center staff for the centers across the country indicate that the Part B Centers for Independent Living are successfully responding to the needs of many disabled citizens. At the same time, overall program management can be improved in several ways. The centers need common definitions and measures of services, client outcomes, and community impacts, even while they continue to respond to the unique needs of individual clients and communities. "Model" information systems would be helpful, even if only developed on an advisory "best practice" basis by the centers themselves. Centers would also benefit from more formal arrangements for exchanging experiences and "best practice" norms with each other, and from technical assistance. Finally, the standards approved by the

National Council for the Handicapped need refinement and promulgation. Finally, a number of policy questions have also been identified for possible resolution by RSA or Congress.

COMPREHENSIVE EVALUATION OF THE TITLE VII, PART B CENTERS FOR INDEPENDENT LIVING PROGRAM

FINAL REPORT

APPENDICES

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APPENDIX A

DEVELOPMENT OF THE INDEPENDENT LIVING CENTER EVALUATION STANDARDS

APPENDIX A

DEVELOPMENT OF THE INDEPENDENT LIVING CENTER EVALUATION STANDARDS

This appendix describes the standards development process, and the relationship between the legislative provision for the standards and the evaluation data elements that accompany the standards. For a description of the Congressional history that prescribed the standards, refer to Chapter I. The standards and their associated data elements are listed in Figure A-1.

DEVELOPMENT OF THE STANDARDS

Standards were developed that reflected the measurement and program design concerns of rehabilitation professionals, consumers of center services, and the centers themselves. This was accomplished through a participatory process that involved expert review from around the country. The standards development process involved eight major steps:

Step 1: The research team developed draft standards drawing on previous work with centers from different parts of the country and other researchers and center evaluators. These standards were refined based on a review of the literature and an iterative review and revision process. The draft standards followed the basic input, process, outcome model, and were designed with maximum flexibility and minimal prescription for how centers would configure their services or activities to accomplish these basic objectives.

Step 2: Proposed standards were distributed by mail for review and comment to over 500 individuals and organizations including independent living centers, disability organizations, researchers, consumer groups, and other disability experts. Comments and suggested revisions, additions and deletions were reviewed and synthesized and the standards were revised to reflect these comments.

Step 3: The revised standards were reviewed with the Project Advisory Committee, including representatives of independent living centers, the National Council on Independent Living (NCIL), the National

Figure A-1

TITLE VII, PART B

INDEPENDENT LIVING CENTER EVALUATION STANDARDS AND CRITERIA

PHILOSOPHY

Standard No. 1: The Center shall promote and practice the following Independent Living Philosophy:

1.1 Consumer control of policy direction and management of the Independent Living Center
1.2 Consumer control of the development of own Independent Living service objectives and services
1.3 Self-help and self-advocacy
1.4 Equal access to society by individuals with disabilities
1.5 Equal access to programs and physical facilities
1.6 Development of peer relationships and peer role models
1.7 Meeting the specific Independent Living needs of the local community
1.8 A range of services to all people with disabilities

TARGET POPULATION

Standard No. 2: The Center shall have a clearly defined target population that includes a range of disabilities.

OUTCOMES AND IMPACTS

Standard No. 3: The Center shall increase individual consumer achievement of Independent Living goals, in areas such as, but not limited to, the following:

3.1 Housing
3.2 Living arrangements
3.3 Income and financial management
3.4 Transportation
3.5 Personal care
3.6 Nutrition
3.7 Household management
3.8 Mobility
3.9 Health and health care

3.10 Assistive devices

3.11 Education

3.12 Employment

3.13 Community involvement

3.14 Family life

3.15 Recreation

3.16 Personal growth

3.17 Social skills

3.18 Communication skills

3.19 Self-direction

3.20 Consumer and legal rights

Standard No. 4: The Center shall increase the availability and improve the quality of community options for Independent Living, in such areas as, but not limited to, the following:

4.1 Housing

4.2 Transportation

4.3 Personal care

4.4 Education

4.5 Employment

4.6 Communication

4.7 Reduction of barriers, including architectural and social

4.8 Disability awareness and social acceptance

4.9 Recreation

4.10 Consumer involvement in civic activities and community affairs

4.11 Physical and mental health care

4.12 Legal services

SERVICES

Standard No. 5: The Center shall provide to disabled individuals within the Center's target population and/or their families the following Independent Living Services:

5.1 Advocacy

5.2 Independent living skills training (e.g., health care, financial management, etc.)

5.3 Peer counseling

In addition to the services above, the Center may provide or make available other services such as, but not limited to, the following:

5.4 Legal services
5.5 Other counseling services (e.g., non-peer, group, family)
5.6 Housing services
5.7 Equipment services
5.8 Transportation services
5.9 Social and recreational services
5.10 Educational services
5.11 Vocational services, including supported employment
5.12 Reader, interpreter, and other communication services
5.13 Attendant and homemaker services
5.14 Electronic services

Standard No. 6: The Center shall provide Information and Referral to all inquirers including those from outside the Center's target population.

Standard No. 7: The Center shall conduct activities to increase community capacity to meet the needs of individuals with disabilities, such as, but not limited to, the following:

7.1 Advocacy and technical assistance services to improve community options, remove community barriers, and create access to public programs
7.2 Public information and education (e.g., presentations, press)
7.3 Outreach to consumers and service providers
7.4 Initiatives to establish an active role in the disabled community

ORGANIZATIONAL MANAGEMENT AND ADMINISTRATION

Standard No. 8: Qualified disabled individuals shall be substantially involved in the policy direction, decision-making, service delivery, and management of the Center, and given preference as:

8.1 Members of Boards of Directors (at least 51% qualified disabled persons)
8.2 Managers and supervisors
8.3 Staff

Standard No. 9: The Center shall establish clear priorities through annual and three-year program and financial planning objectives which include, but are not limited to, the following:

9.1 Overall Center goals or mission

9.2 Work plan for achieving goals

9.3 Specific objectives for numbers and disabilities of individuals to be served

9.4 Service priorities and needs to be addressed

9.5 Types of services to be provided and service delivery procedures

9.6 Annual, three-year, and alternative budget projections

Standard No. 10: The Center shall use sound organizational and personnel management practices.

10.1 Written policies and procedures for Board and staff which specify appropriate roles and responsibilities

10.2 Job descriptions for all personnel, including volunteers

10.3 Clear lines of authority and supervision

10.4 Personnel performance appraisal and guidance

10.5 Equal opportunity and affirmative action policies and procedures

10.6 Staff and Board training and development

Standard No. 11: The Center shall practice sound fiscal management.

11.1 Annual budget that identifies funding sources, and the allocation of resources across services and activities

11.2 Budget monitoring system and procedures for managing cash flow

11.3 Annual audit by independent public accountant

11.4 Resource development activities (e.g., fund raising, grant development, securing fee-for-service agreements, business development, endowment funds, permanent government funding) appropriate to achievement of objectives

11.5 Determination of costs of services and activities (total program cost, cost by funding source, service component costs, average cost per service and per individual served)

EVALUATION

Standard No. 12: The Grantee and the Centers shall conduct annual self-evaluations and shall maintain records adequate to measure performance on these Independent Living Center Evaluation Standards, including:

12.1 Documentation of the number and types of individuals served (age, disability or relationship to disabled individual, gender, living arrangement, ethnicity, services received)

12.2 Documentation of the types and units of services provided to individuals and the community

12.3 Documentation of individual outcomes

12.4 Documentation of community Independent Living impacts

12.5 Client intake, service planning, and progress reports

12.6 Management records, including financial, legal, administrative personnel, and interagency agreements

12.7 Consumer evaluation of quality and appropriateness of the Center program

Council on the Handicapped (NCH), the Council of State Administrators of Vocational Rehabilitation (CSAVR), and the U.S. Department of Education. The standards were revised to reflect Advisory Committee recommendations.

Step 4: The standards were presented to the Adult Services Committee of the National Council on the Handicapped, and the full Council, during the regularly-scheduled meeting in November 1984. The Council recommended changes to several standards.

Step 5: The standards were further reviewed and revised by staff of the Rehabilitation Services Administration and the Office of Special Education and Rehabilitation Services. During this review, the RSA Commissioner met with the Executive Director of the National Council and contract staff to discuss final standard wording and recommendations for Council consideration.

Step 6: The standards were reviewed by the National Council on the Handicapped, further revised to reflect Council recommendations, and then approved in January 1985.

The set of standards approved by the Council to guide this evaluation reflects the concerns and points of view of many concerned individuals and organizations. They are designed to capture important aspects of the centers as they currently exist. The standards offer more guidance for program design than the original drafts and thus offer potential as program standards as well as criteria for evaluation.

RELATIONSHIP BETWEEN LEGISLATIVE PROVISIONS AND THE EVALUATION DATA ELEMENTS THAT ACCOMPANY THE STANDARDS

Each legislative provision is addressed by specific standards containing evaluation questions (data elements) needed to answer the provision. In this section, the relationships among the provisions, the evaluation standards, and the questions addressed by the evaluation are detailed. For references to specific data element numbers, see Table I-1 in Chapter I of the report.

A. The Number and Types of Handicapped Individuals Assisted

and

B. The Extent to Which Handicapped Individuals with Varying Handicapping Conditions Were Served

The population served by centers is addressed in Standards 1, 2, 9, and 12. The evaluation questions are:

- Are centers providing equal access for individuals with different types of disabilities to their programs and physical facilities?
- To what extent do centers provide a range of services to all people with disabilities?
- What range of disabilities is served by the centers?
- Are target population goals specified?
- Do centers have specific objectives for numbers and disabilities of individuals to be served?
- Do centers record the number and types of individuals served?

C. The Types of Services Provided

The types of services offered by centers are addressed in Standards 1, 5, 6, 9, and 12. The specific evaluation questions are:

- To what extent do consumers control their own service objectives and service delivery?
- Do centers promote self-help and self-advocacy?
- Do centers develop peer relationships and peer role models?
- Do the centers provide advocacy, independent living skills training, and peer counseling? To what extent are other services -- legal, other counseling, housing, equipment, transportation, social/recreational, educational, vocational, communication, attendant/homemaker, and electronic services -- provided?
- Is information and referral assistance provided to all inquirers regardless of their type of disability?

- To what extent do centers specify one- and three-year service priorities and needs to be addressed?
- To what extent do centers specify, for one- and three-year planning, the types of services to be provided and service delivery procedures?
- To what extent do centers document the types and units of services to individuals? To the community?

D. The Sources of Funding

and

E. The Percentage of Resources Committed to Each Type of Service Provided

The funding sources and patterns of allocation are addressed in Standards 11 and 12. The evaluation questions are:

- Do centers have an annual budget that identifies funding sources and the allocation of resources across services and activities?
- Can centers determine costs of services and activities?
- Do centers maintain management records?

F. How Services Provided Contributed to the Maintenance or the Increased Independence of Handicapped Individuals Assisted

The impact of center services on consumers of those services is addressed in Standards 3 and 12. The evaluation questions are:

- Did services increase consumer goal achievement in housing, living arrangements, finances, transportation, personal care, nutrition, household management, mobility, health, assistance devices, education, employment, community involvement, family life, recreation, personal growth, social skills, communication skills, self-direction, and consumer and legal rights?
- To what extent did center services contribute to consumers' ability to maintain their level of independence?

- To what extent do centers document individual consumer outcomes?

G. The Extent to Which Handicapped Individuals Participate in Management and Decision-Making in the Center

The extent of consumer participation in management and decision-making was addressed in Standards 1, 8, 10, and 12. The evaluation questions are:

- Do centers promote consumer control of policy direction and management?
- What percentage of the (1) Board of Directors, (2) managers and supervisors, and (3) staff are disabled?
- Are roles and responsibilities of Board and staff specified?
- Are job descriptions provided for all personnel, including volunteers?
- Are there clearly specified lines of authority and supervision?
- Do the centers have systems for personnel performance appraisal and guidance?
- Are there equal opportunity and affirmative action policies and procedures?
- Are there opportunities for staff and Board training and development?
- To what extent do centers have consumer evaluations of quality and appropriateness of the center program?

H. The Extent of Capacity-Building Activities, Including Collaboration With Other Agencies and Organizations

and

I. The Extent of Catalytic Activities to Promote Community Awareness, Involvement, and Assistance

and

J. The Extent of Outreach Efforts and the Impact of Such Efforts

The extent of community activity and involvement is addressed by Standards 1, 4, 6, 7, 11, and 12. The evaluation questions are:

- Do centers promote equal access to society for individuals with disabilities?
- Do centers address the specific needs of the local disabled community?
- Do centers increase community options in housing, transportation, personal care, education, employment, communication, reduced barriers, disability awareness, consumer involvement in civic activities, health care, and legal services?
- Is information and referral provided to all inquiries?
- How many centers provide advocacy and technical assistance, public information, outreach to consumers and service providers, and participate actively in the disabled community?
- To what extent do centers conduct resource development activities?
- Do centers document community impacts?

K. A Comparison, When Appropriate, of Prior Year(s) Activities With Most Recent Year Activities

A comparison of centers over time is addressed by Standards 9, 11, and 12. The evaluation questions are:

- Do centers have annual and three-year planning goals?
- Do centers have an annual work plan for addressing goals?
- Do centers have specific annual and thee-year objectives for numbers and disabilities of individuals to be served?

- Do centers specify one- and three-year service priorities?
- Do centers specify for one- and three-year planning the types of services to be provided and the service delivery procedure?
- Do centers have annual, three-year, and alternative budget projections?
- Do centers have an annual budget that identifies funding sources and the allocation of resources across services and utilities?
- Do centers have a budget monitoring system and procedures for managing cash flow?
- Do centers have an annual audit by an independent public accountant?
- Can centers determine costs of services and activities?
- Do centers record the number and types of individuals served?
- Do centers document the types and units of services to individuals and the community?
- Are individual client outcomes documented by centers?
- Are community independent living impacts documented by centers?
- Do centers have client intake records, service planning records, client progress records?
- Do centers maintain management records (financial, legal, administrative, personnel, interagency agreements)?
- Do centers provide opportunities for consumers to evaluate the appropriateness and quality of the center?

APPENDIX B

DATA COLLECTION INSTRUMENTS

OMB Approval No. 1820-0531
Expiration Date: 2/86

BPAID ____

TITLE VII PART B CENTER MAIL SURVEY

Please print or type your responses

DESCRIPTION OF CENTER OR PROGRAM

Name of IL Center ____________________

Address ____________________

____

Name and Title of Person Responding ____________________
Name

____
Title

Should be the person most directly responsible for IL Center operations

(   ) ____________________
Telephone Number

____
Date

1. How many years has the IL Center been: [ANSWER BOTH]

Answer both

in operation? ______ years

receiving Part B funding? ______ years

2. For your current funding year, what is the annual amount of the IL Center's:

Please give all amounts

Federal Part B funding $ ____________

Part B match (if any) $ ____________

Other direct federal funding $ ____________

State funding $ ____________

Local government funding $ ____________

Private funding $ ____________

Other funding (SPECIFY) $ ____________

____

TOTAL CURRENT ANNUAL IL BUDGET $ ____________

3. How does the Center receive its federal (Part B) funding? [CHECK ONE]

Check one

☐ As a direct recipient

☐ Through the state VR agency

☐ As a subcontractor to another agency (WHAT AGENCY?) ________

____

4. How is Part B funding used? [CHECK ALL THAT APPLY]

Check all that apply

☐ Use of Part B funds is limited to specific service(s)

WHICH SERVICE(S)? ____________________

☐ Use of Part B funds is limited to serving specific disability group(s)

WHICH GROUP(S)? ____________________

☐ Part B is used to support a few specific staff positions

DESCRIBE POSITIONS ____________________

____

☐ Part B funds supplement overall Center activity

☐ For other purposes (SPECIFY) ____________________

____

5. Is your organization: [CHECK ONE]

Check one

☐ an independent IL Center [GO TO QUESTION #6]

☐ an IL Center which is part of a larger agency

☐ an IL program or activity within a larger agency (not a Center)

IF PART OF A LARGER AGENCY:

Name of agency ____________________

Address ____________________

Size of agency annual budget $ ____________________

Type of agency: [CHECK ONE]

Check one

☐ government

☐ private nonprofit

☐ private for-profit

Target population of agency services ____________________

Types of services other than IL offered by agency ____________________

____

6. Is your service area: [CHECK ONE]

Check one

☐ Urban
☐ Rural
☐ Suburban

7. Does your IL Center serve the entire state or part of the state? [CHECK ONE]

Check one

☐ The entire state
☐ Part of the state

8. Please score each statement on the degree to which you agree it describes the **strongest** emphases in your IL Center's current program. [CIRCLE ONE NUMBER FOR EACH ITEM]

Circle one number for each item

	Strongly Disagree				Strongly Agree
Persons with disabilities control the policy direction and management of the Center	1	2	3	4	5
Persons with disabilities establish Center service priorities	1	2	3	4	5
Persons with disabilities manage Center operations	1	2	3	4	5
Persons with disabilities serve in important staff roles	1	2	3	4	5
Consumers control the development of their own IL service objectives and services	1	2	3	4	5
Center encourages consumer self-help and self-advocacy	1	2	3	4	5
Equal consumer access to Center programs and physical facilities	1	2	3	4	5
Center encourages peer role models and peer relationships	1	2	3	4	5
Center works to guarantee equal access to society by individuals with disabilities	1	2	3	4	5
Center provides a range of services to all people with disabilities	1	2	3	4	5
Center works to meet the specific IL needs of the local community	1	2	3	4	5

ORGANIZATIONAL MANAGEMENT AND ADMINISTRATION

9. Is the IL Center Executive Director disabled? [CHECK ONE]

Check one

☐ Yes
☐ No

10. Please indicate the total number of individuals in the following policy, management, and staff roles in the IL Center, and for each, the number of persons with disabilities.

Please give all amounts

	Total Number	Number with Disabilities
On Board of Directors	____	____
IL Advisory Committee or Board	____	____
IL Administrators or Program Directors	____	____
IL direct service staff	____	____
IL clerical/support staff	____	____
Other paid IL staff	____	____
IL volunteers	____	____

11. Below are examples of procedures being used at some Centers. This does not mean that all are appropriate to your Center. Please indicate whether or not each procedure is **currently in operation and actually used at your Center.** [CHECK YES OR NO FOR EACH ITEM]

Check yes or no for each item

Yes	No	
☐	☐	Written ILC mission or goal statement reflecting IL philosophy
☐	☐	Formal annual planning procedures
☐	☐	Annual service priorities and needs to be addressed
☐	☐	Specific objectives for numbers and types of disabilities to be served this year
☐	☐	Three-year plans for services and consumers to be served
☐	☐	Written work plans with timelines for achieving objectives
☐	☐	Written description of ILC services and service delivery procedures
☐	☐	Annual budget projection
☐	☐	Long-term budget projection (_____ years)
☐	☐	Written policies and procedures for Board and staff specifying roles and responsibilities
☐	☐	Written personnel policies and procedures
☐	☐	Written job descriptions for all personnel
☐	☐	Organizational chart showing job responsibilities, authority, and supervision
☐	☐	Written affirmative action and equal opportunity policies and procedures
☐	☐	Written personnel performance evaluations at least once a year for all staff
☐	☐	Center-supported Board training and development
☐	☐	Center-supported staff training and development
☐	☐	Annual budget that identified funding sources and resource allocation
☐	☐	Budget monitoring system

(CONTINUED)

Yes	No	
☐	☐	Procedures for managing cash flow
☐	☐	Annual audit by independent public accountant
		Resource development activities:
☐	☐	Grant development
☐	☐	Fee-for-service agreements
☐	☐	Business development
		Accounting procedures that produce information on:
☐	☐	Total program cost
☐	☐	Costs by funding source
☐	☐	Costs by service component
☐	☐	Average cost per service
☐	☐	Average cost per individual served
☐	☐	Computerized fiscal systems
☐	☐	Consumer intake records
☐	☐	Written consumer service plans
☐	☐	Consumer progress records
☐	☐	Documentation of the number and types of consumers served (unduplicated counts)
☐	☐	Documentation of the types and units of services provided (e.g., number of service hours)
☐	☐	Evaluation report documenting individual and community independent living outcomes and impacts at least once a year
☐	☐	Computerized client information system
☐	☐	Documentation of specific levels of IL goal achievement by individual clients
☐	☐	Computerized service system

ORGANIZATIONAL RELATIONSHIPS

12. Please indicate the types of relationships your Center has with the types of agencies listed. [SHOW ALL RELATIONSHIPS WITH EACH TYPE OF AGENCY]

Nature of Relationship (enter all that apply using codes listed below)	Agency Type
______________________	Other independent living Centers
______________________	State Vocational Rehabilitation agency
______________________	Rehabilitation facility
______________________	Primary care facility (hospital, nursing home)
______________________	Doctor or medical care provider
______________________	Mental retardation/mental health agency
______________________	Special education agency/program
______________________	Other educational organization
______________________	Housing agency
______________________	Medicaid agency
______________________	Advocacy group
______________________	Lobbying groups
______________________	Legal service organization
______________________	Disability-related organization
______________________	Agency for aging
______________________	Employment service
______________________	Transportation service
______________________	Social Security office
______________________	Welfare or social service agency
______________________	Private vendors or services
______________________	Business/corporations
______________________	Other (SPECIFY) ______________________

CODES TO BE ENTERED ABOVE TO DESCRIBE TYPES OF RELATIONSHIPS

A = We refer many of our consumers to them

B = We refer a few of our consumers to them

C = We receive many of our consumers through referrals from this agency

D = We receive a few of our consumers through referrals from this agency

E = We coordinate with them in providing services to consumers

F = We coordinate with them on communication and advocacy

G = We provide them with information on technicall assistance

H = They provide us with information or technical assistance

I = We receive funding or other support from them

J = They purchase services from us

K = We purchase specific services from them

L = Other (SPECIFY) ______________________

M = Other (SPECIFY) ______________________

N = Other (SPECIFY) ______________________

O = We have no relationship with an agency of this type

13. Consumers of IL Services
This question refers to direct client services, including information and referral.

a. How many consumers used your services last month? ______________

Is this an ☐ exact count or ☐ best estimate

b. How many consumers has your Center served in the last year? (unduplicated count) ______________

Is this an ☐ exact count or ☐ best estimate

c. Please indicate the **primary disability** of those consumers served last year. (The total for these categories should be the same as the answer to Question 13.b, above.)

Please give all amounts

These numbers are:
☐ *exact count*
☐ *best estimate*

	Number Served
Blindness (both eyes)	___________
Other visual impairment	___________
Deafness	___________
Other hearing impairment	___________
Amputation or absence of limb(s)	___________
Spinal cord injury	___________
Other orthopedic impairment (e.g., arthritis, cerebral palsy, polio, multiple sclerosis)	___________
Mental illness	___________
Mental retardation	___________
Other disabling conditions (e.g., diabetes, epilepsy, stroke, head injury, etc.)	___________
Not disabled (e.g., parents, family members, sponsors, friends)	___________
Disability category unknown	___________
TOTAL (same as 13.b, above)	______________

d. Of the total number of consumers receiving your services last year, what percentage received only "Information and Referral" services?

________ %

SERVICES DELIVERED

14a. For the following possible IL services, please indicate how much of each service your Center provided to consumers in the last year.
IF YOU DID NOT PROVIDE THE SERVICE DIRECTLY, check Column A or B.
IF YOU DID PROVIDE THE SERVICE, indicate:
the **number of consumers served** in Column C,
the **number of service units** in Column D, and
the **type of service unit** (e.g., hours, contacts, trips) in Column E.

Ⓐ Referred to Another Agency	Ⓑ Not Provided at All	Service	Ⓒ Number of Consumers	Ⓓ Number of Service Units	Ⓔ Type of Service Unit
☐	☐	Advocacy			
☐	☐	Independent Living Skills Training (i.e. financial management, communication self-care, etc.)			
☐	☐	Peer counseling			
☐	☐	Legal and paralegal services			
☐	☐	Professional counseling (licensed or certified)			
☐	☐	Other counseling services (e.g.,non-peer, family, group)			
☐	☐	Housing services			
☐	☐	Equipment services			
☐	☐	Transportation services			
☐	☐	Social and recreation services			
☐	☐	Educational services			
☐	☐	Vocational services, including supported employment			
☐	☐	Interpreter, reader, and other communication services			
☐	☐	Attendant and homemaker services (evaluations, training, monitoring, etc.)			
☐	☐	Electronic services			
☐	☐	Family support services			
☐	☐	Information and referral			
☐	☐	Other (SPECIFY) ________			
☐	☐	________			

14 b. How does your IL Center provide most of its services? [CHECK ONLY ONE]

Check only one

☐ Mostly over the phone

☐ Mostly in person

☐ Through a combination of in-person/over-the-phone in equal amounts

☐ Other (HOW?) ________________________________

c. Please estimate the number of consumers you referred to other agencies for service last year.

____

d. Please estimate the number of consumers referred to your Center by other agencies and organizations last year.

____

15. Which of the following community development areas represents the primary target of your community efforts? [CHECK ALL THAT APPLY]

Check all that apply

☐ Housing options

☐ Transportation options

☐ Personal care availability

☐ Educational options

☐ Employment opportunities

☐ Communication

☐ Reduction of barriers (architectual and social)

☐ Disability awareness and social acceptance

☐ Recreation

☐ Consumer involvement in civic activities and community affairs

☐ Physical and mental health care

☐ Legal services

16. Of your total IL activities, please estimate the percentage devoted to:

Individual services ________ %

Community development ________ %

17. Does your Center or agency offer residential services to disabled IL consumers? [CHECK ONE]

Check one

☐ Yes

What type of services? [CHECK ALL THAT APPLY]

☐ Residence in group home with agency staff
☐ Residence in separate home or apartment with agency staff
☐ Independent residence in separate home or apartment
☐ Transitional residence program
☐ Temporary or emergency housing provided
☐ Other (SPECIFY) ______________________________

☐ No

CENTER CHARACTERISTICS

18. We understand that you are not able to isolate changes in client status that are caused by the Center's program. However, please estimate the number of consumers who exhibited the following characteristics in the past year. If the specified characteristic is not expected in your service program, indicate "NA." Please check if your response is based on accurate records or on estimates.

Enter the Number of Consumers		Records	Estimate
______	Obtained modifications in own housing to improve accessibility	☐	☐
______	Moved from an institution (hospital, nursing home) to a less restrictive setting	☐	☐
______	Obtained financial benefits	☐	☐
______	Learned to use public and/or other available transportation options	☐	☐
______	Acquired license to drive	☐	☐
______	Acquired attendants, visiting nurses, homemakers, cooks, etc	☐	☐
______	Acquired readers or interpreters	☐	☐
______	Obtained specific services by Center referral to another program	☐	☐
______	Became able to carry out household and shopping chores	☐	☐
______	Acquired appropriate mobility, communication or vision aids	☐	☐
______	Achieved educational goals	☐	☐
______	Obtained employment	☐	☐
______	Registered to vote	☐	☐
______	Gained memberships in community governing boards, committees, councils	☐	☐
______	Other (SPECIFY) ______________________________ ______________________________	☐	☐
______	Other (SPECIFY) ______________________________ ______________________________	☐	☐
______	Other (SPECIFY) ______________________________ ______________________________	☐	☐

19. We realize it is not possible to isolate changes that are caused by Center programs. However, please estimate community changes you feel you contributed to in the last year. If the specified change is not expected in your program, indicate "NA."

Enter the Number of Each Type of Change that Occurred Last Year		Records	Estimate
______	Housing units made accessible	☐	☐
______	Accessible vehicles added to public transportation system	☐	☐
______	Qualified attendants added to community attendant pool	☐	☐
______	Qualified readers added to community reader pool	☐	☐
______	Qualified interpreters added to community interpreter pool	☐	☐
$ ______	Amount of additional funding made available for attendants, readers, and/or interpreters	☐	☐
______	Agreements established with special education programs or other agencies	☐	☐
______	Educational resources made accessible to students with disabilities	☐	☐
______	Jobs developed for persons with disabilities	☐	☐
______	Communications devices (e.g., number of devices) made available to community	☐	☐
______	Public buildings with increased accessibility	☐	☐
______	Ramps or curb cuts	☐	☐
______	Brailled information	☐	☐
______	Additional handicapped parking spaces	☐	☐
______	Elevators with brailled letters and numbers	☐	☐
______	Recreation programs available to persons with disabilities	☐	☐
______	Health providers trained in special needs of persons with disabilities	☐	☐
______	Other service providers trained in special needs of persons with disabilities	☐	☐
______	Other (SPECIFY) ______________________________ ______________________________	☐	☐
______	Other (SPECIFY) ______________________________ ______________________________	☐	☐
______	Other (SPECIFY) ______________________________	☐	☐

CENTER OBSERVATIONS

20. What do you think has been the most significant contribution of your Center:

-- to individuals with disabilites? ____________________

____

____

____

____

____

-- to the community at large? ____________________

____

____

____

____

____

21. Do you have any comments you would like to add?

____

____

____

____

____

____

THANK YOU very much for your time and thought in answering these questions. The information you have provided will be most helpful to us.

Please return the completed form in the enclosed pre-stamped envelope **IMMEDIATELY** to:

Independent Living Evaluation Project
Research & Training Center on IL
BCR/348 Haworth
University of Kansas
Lawrence, KS 66045

OMB Approval No. 1820-0531
Expiration Date: 2/86

BPAID ☐☐☐☐☐

CONSUMER MAIL SURVEY

Please mark your answers by putting an X in the right box X or by filling in the blank. In most questions, you should check only one box. In some questions, you are told to "CHECK ALL THAT APPLY." For these questions, check as many boxes as describe you or your situation.

The questionnaire is divided into three parts. In the first part, you are asked for general information about yourself. The second part asks about your experiences with this independent living center. The last part asks about the effect the center has had on you.

Please feel free to add comments you may have on any of the questions.

I. GENERAL INFORMATION

The first set of questions are general information questions about you and your situation.

1. How old are you? __________years

2. Are you ☐ Male ☐ Female

3. What is your race or ethnic background? [CHECK ONLY ONE]

Check Only One

☐ White (except Hispanic)
☐ Black
☐ Hispanic (Spanish surname)
☐ Asian
☐ Native American
☐ Other (SPECIFY):______________________________

CHECK ONE:

I completed this survey by myself ☐
I completed this survey with help from someone else ☐
Someone else completed this survey for me ☐

4. What is your disability?

	Major Disability [CHECK ONLY ONE]	Other Disabilities [CHECK ANY THAT APPLY]
Blindness (both eyes)	☐	☐
Other Visual Impairment	☐	☐
Deafness	☐	☐
Other Hearing Impairment	☐	☐
Orthopedic Impairment:		
Arthritis	☐	☐
Cerebral Palsy	☐	☐
Polio	☐	☐
Multiple Sclerosis	☐	☐
Muscular Dystrophy	☐	☐
Spinal Cord Injury	☐	☐
Amputation or Absence of Limbs	☐	☐
Other (SPECIFY): ________	☐	☐
Mental Illness	☐	☐
Mental Retardation	☐	☐
Other Disabling Conditions:		
Diabetes	☐	☐
Epilepsy	☐	☐
Head Injury	☐	☐
Stroke	☐	☐
Other (SPECIFY): ________	☐	☐
Not Disabled:		
Parent of Disabled Child	☐	☐
Spouse or Friend of Disabled	☐	☐
Other (SPECIFY): ________	☐	☐

5. How old were you when you became disabled?

☐ years ☐ I was disabled at birth ☐ I am not disabled

6. Do you currently use any of the following? [CHECK ALL THAT APPLY]

Check All That Apply

- ☐ Electric wheelchair
- ☐ Manual wheelchair
- ☐ Walker
- ☐ Crutches or walking cane
- ☐ Seeing eye dog
- ☐ White cane
- ☐ Other mobility aid [WHAT KIND?] ____________________
- ☐ None used

7. Do you regularly use any of the following? [CHECK ALL THAT APPLY]

Check All That Apply

- ☐ An attendant
- ☐ A reader
- ☐ An interpreter
- ☐ A housekeeper or cook
- ☐ Other personal helper [WHAT KIND?]____________________
- ☐ None used

8. Are you now, or have you ever been, a Vocational Rehabilitation (VR) Client? [CHECK ONLY ONE]

Check Only One

- ☐ I am a Rehabilitation client now
- ☐ I am not a Rehabilitation client now, but I was before
- ☐ I have never been a Rehabilitation client
- ☐ I don't know

II. EXPERIENCE WITH THE IL CENTER

The next set of questions are about your experiences with the independent living (IL) center.

9. How did you first hear about this independent living center? [CHECK ONLY ONE]

Check Only One

☐ From a friend
☐ From someone on the IL Center staff
☐ From a doctor or other medical person or health agency
☐ At school
☐ From a Department of Vocational Rehabilitation Office
☐ From another government agency
☐ From the newspaper, radio, or TV
☐ Other (SPECIFY):______________________________

10. Have you ever visited the IL Center?

☐ Yes ☐ No

11. When did you first visit or talk to someone from this independent living center? [CHECK ONLY ONE]

Check Only One

☐ In 1985
☐ In 1984
☐ In 1983
☐ Before 1983
☐ Don't know

12. How many times have you ever visited or talked to someone from this IL Center? [CHECK ONLY ONE]

Check Only One

☐ One or two times
☐ Three to five times
☐ Six to ten times
☐ Eleven to twenty times
☐ More than twenty times

13. Where do you generally receive services from the Center? [CHECK ONLY ONE]

Check Only One

☐ At the Center
☐ Over the phone
☐ Where I live

14. When was your most recent contact with this IL Center? [CHECK ONLY ONE]

Check Only One

☐ In the past week
☐ More than a week ago, but within the last month
☐ More than a month ago, but within the last six months
☐ More than six months ago

15. How easy is it for you to get to the IL Center? [CHECK ALL THAT APPLY]

Check All That Apply

☐ It is near public transportation I can use
☐ It is in a building that is easy to enter and leave
☐ It is easily reached by phone
☐ The Center provides transportation
☐ The Center is not easy for me to get to
☐ I never go to the Center

16. For the services you get from the IL Center, who was **MOST** responsible for setting your independent living goals? [CHECK ONLY ONE]

Check Only One

☐ Myself
☐ Someone on the Center staff
☐ Someone in another agency
☐ Someone in my family
☐ Other (WHO?) ________________________________

17. Who is **MOST** responsible for choosing which services you receive from the IL Center? [CHECK ONLY ONE]

Check Only One

☐ Myself
☐ Someone on the Center staff
☐ Someone in another agency
☐ Someone in my family
☐ Other (WHO?) ______________________________

18. In using IL Center services, did you work with one individual who helped coordinate all the services you received?

☐ Yes ☐ No

19. What is your **major** purpose in using the IL Center? [CHECK ONLY ONE]

Check Only One

☐ To get information about the programs, services and benefits
☐ To get a variety of services which increase my independence by changing my housing, self care skills, or life style.
☐ To get assistance which helps me maintain my current level of independence.
☐ Other (WHAT PURPOSE?) ______________________________

20. Describe IL Center staff members you have worked with most **often:** [CHECK ALL THAT APPLY]

Check All That Apply

☐ Have a disability like mine
☐ Have a disability different from mine
☐ Have no disability that I know of

21. Are there individuals with disabilities in important jobs in the IL Center? [CHECK ONLY ONE]

☐ Yes ☐ No ☐ I don't know

22. Have you helped in the IL Center in any of the following ways? [CHECK ALL THAT APPLY]

Check All That Apply

☐ As a volunteer staff member
☐ As a paid staff member
☐ On an Advisory Committee
☐ On the Board of Directors
☐ Evaluating services
☐ Other (WHAT HELP?) ____________________
☐ No, I haven't helped

23. What services did you receive at the IL Center? [CHECK ALL THAT APPLY]

Check All That Apply

☐ Information and referral
☐ Advocacy
☐ Independent living skills training (e.g., money management, cooking, self care, braille)
☐ Peer counseling
☐ Other counseling services (individual, group, or family)
☐ Legal services
☐ Housing services
☐ Equipment services
☐ Transportation services
☐ Social and recreational services
☐ Educational services
☐ Vocational services
☐ Reader, interpreter, and other communication services
☐ Attendant or homemaker (personal assistance) services
☐ Electronic services (devices, computers)
☐ Other (WHICH SERVICES?) ____________________

____

____

24. Please rate the IL Center on the following items. If you judge the Center as Very Good on any item, circle the "5". If the Center is Very Poor for the item, circle "1". If it is in between, circle the "2" "3" or "4". If the item does not apply to you, circle "N/A." [CIRCLE ONE NUMBER FOR EACH ITEM]

Circle One Number for Each Item

	Very Poor				Very Good	Not Applicable
Helping me get services easily and quickly	1	2	3	4	5	N/A
Helping me get benefits and services from other places	1	2	3	4	5	N/A
Allowing me to define my own service goals	1	2	3	4	5	N/A
Allowing me to have control over my services	1	2	3	4	5	N/A
Helping me increase my independence	1	2	3	4	5	N/A
Improving the community for all persons with disabilities	1	2	3	4	5	N/A
Involving disabled people in running the IL Center	1	2	3	4	5	N/A
Establishing a ledership role in the disabled community	1	2	3	4	5	N/A

III. RESULTS OF CENTER SERVICES

These last questions are about changes in your situation since contacting the Center, and the effect the Center has had on you.

25. Where did you live before you had contact with the Center and where do you live now? [CHECK ONLY ONE IN EACH COLUMN]

Where I Lived Before Contact with Center	Where I Live Now	
☐	☐	Institution or primary care facility (e.g., hospital, nursing home)
☐	☐	In parents' (or guardian's) home
☐	☐	Supervised residence or group home
☐	☐	Transitional or independent living training residence
☐	☐	Cooperative or shared residence
☐	☐	In my own house or apartment
☐	☐	Other (WHERE? ANSWER BELOW IF YOU CHECK "Other")

Before contact with Center, I lived ____________

____

I now live ______________________________________

26. Does your current housing situation allow you to be more or less independent than your previous situation?

___ More ___ Less

Did the Center help you change your housing situation?

___ Yes ___ No

27. Has your **educational level** changed since you first contacted the center?

☐ Yes ☐ No [GO TO QUESTION #29]

If yes, did the Center help you continue your education?

☐ Yes ☐ No

28. Tell us about your level of education before contact with the Center and now.

Before Contact with Center	Now	
☐	☐	a. Less than 9th grade
☐	☐	b. Some high school
☐	☐	c. Finished high school
☐	☐	d. Some College
☐	☐	e. Some graduate work
☐	☐	f. Graduate degree (e.g., M.A., Ph.D.)

29. Please tell us about your employment situation. Are you working now,and were you working before contact with the Center? Indicate what your employment situation was before you were in contact with the Center, and your employment situation now. [CHECK ONLY ONE IN EACH COLUMN]

Before Contact with Center	Now	
☐	☐	a. Working full-time (minimum wage or more)
☐	☐	b. Working part-time (minimul wage or more)
☐	☐	c. Sheltered work (less than minimum wage)
☐	☐	d. Volunteer (unpaid)
☐	☐	e. Not working
☐	☐	f. Retired

30. Has your **employment** situation changed since you were in contact with the Center?

☐ Yes ☐ No [GO TO QUESTION #31]

If yes, is your employment situation better or worse?

☐ Better ☐ Worse

Did the Center help you with your employment situation?

☐ Yes ☐ No

31. Please check X the income sources you were receiving when you first visited or talked to someone at the IL Center, and X the income sources you have now. [CHECK ALL THAT APPLY]

Check All That Apply

	Sources I Had Before	Sources I Have Now
Job earnings from employment	☐	☐
Support from family (including spouse)	☐	☐
SSI (gold check)	☐	☐
SSDI (green check)	☐	☐
Social Security	☐	☐
AFDC (Aid to Families with Dependent Children)	☐	☐
Personal Care/Attendant/Homemaker	☐	☐
General Assistance (welfare)	☐	☐
Worker's Compensation	☐	☐
Veteran's Benefits	☐	☐
Insurance Benefits	☐	☐
Housing Subsidy	☐	☐
Pension	☐	☐
Alimony	☐	☐
Other (SPECIFY): ________________ ________________	☐	☐

32. Has your monthly income changed since you first visited or contacted someone at the Center?

☐ Yes ☐ No [GO TO QUESTION #34]

If yes, is it higher or lower?

☐ Higher ☐ Lower

Did the Center help you increase your income?

☐ Yes ☐ No [GO TO QUESTION #34]

33. What was your monthly income before contact with the Center and what is your monthly income now?

Before Contact With Center	Now	
☐	☐	Less than $199/month
☐	☐	$200 to $399/month
☐	☐	$400 to $599/month
☐	☐	$600 to $799/month
☐	☐	$800 to $999/month
☐	☐	$1,000 to $1,999/month
☐	☐	Over $2,000/month

34. How do do you get where you need to go? What is your transportation situation? [CHECK ALL THAT APPLY]

Check All That Apply

☐ I use public transportation

☐ I drive myself

☐ I have a driver to drive my car or van

☐ I use special transportation services (e.g., van service)

☐ I take a taxi

☐ I have a friend or family member to take me places

35. Has your transportation situation changed since contacting the Center?

☐ Yes ☐ No [GO TO QUESTION #37]

If yes, is your transportation situation better or worse?

☐ Better ☐ Worse

Did the Center help you with your transportation situation?

☐ Yes ☐ No

36. Where were you able to go independently before contacting the Center? Where are you able to go independently now? [CHECK ALL THAT APPLY]

Check All That Apply

	Where I Went Before	Where I Go Now
Medical care	☐	☐
Personal business	☐	☐
IL Center	☐	☐
Community agencies	☐	☐
Work/School	☐	☐
Community activities	☐	☐
Other (SPECIFY): ____________________	☐	☐

37. Please tell us about any PERSONAL or SOCIAL CHANGES in your life that you believe resulted from your contact with the Center. Check the Yes or No column below for each area to indicate whether the Center did or did not affect your personal situation. [CHECK ALL THAT APPLY]

Check All That Apply

Since I first contacted the Center, I:

Yes	No	
☐	☐	Feel more comfortable in public
☐	☐	Participate more comfortably in social situations
☐	☐	Am able to cope with my disability and attitudes toward disability
☐	☐	Feel better about sexuality and personal relationships
☐	☐	Belong to more community groups
☐	☐	Have more friends to share social activities
☐	☐	Feel more self-confident
☐	☐	Communicate more assertively and effectively
☐	☐	Participate more in recreational sports activities
☐	☐	Am more healthy and physically fit
☐	☐	Other (WHAT CHANGES?)________________________________
☐	☐	Am no different from before

38. Please tell us about any AIDS, BENEFITS, or SERVICES that you believe you acquired through the assistance of the Center. Check the Yes or No column for each item to indicate whether the Center did or did not help you acquire the item. [CHECK ALL THAT APPLY]

Check All That Apply

Yes	No	
☐	☐	Attendant
☐	☐	Reader
☐	☐	Interpreter
☐	☐	Mobility aid
☐	☐	Communication or vision aid
☐	☐	Adaptive equipment (environmental control unit, door opener, page turner, buzzer system, brailler)
☐	☐	Equipment repair or maintenance service
☐	☐	Legal or advocacy services
☐	☐	Other (SPECIFY): ________________________________
☐	☐	None

Check All That Apply

39. Please tell us about SKILLS you believe you acquired through participation in Center services that helped you become more independent. Check the Yes or No column for each item to indicate whether the Center did or did not help you develop the particular skill to improve your ability to live more independently. [CHECK ALL THAT APPLY]

The Center has helped me learn to:

Yes	No	
☐	☐	Confront infringement of my rights or unacceptable conditions
☐	☐	Manage my personal finances
☐	☐	Acquire necessary medical and/or community services
☐	☐	Carry out basic household and shopping chores
☐	☐	Acquire necessary household support services
☐	☐	Establish and carry out daily/weekly self care routines
☐	☐	Use and manage personal care attendant services (find, interview, hire, and employ)
☐	☐	Effectively use equipment and/or aids
☐	☐	Identify and coordinate community resources to increase independence
☐	☐	Acquire or use available transportation
☐	☐	Develop a career plan or life goal plan
☐	☐	Other (WHAT SKILLS?)________________________________
☐	☐	None of these

40. Please tell us about any useful KNOWLEDGE or information you believe you gained as a result of participating in services. Check the Yes or No column for each item to indicate whether the Center did or did not help you to increase your knowledge and understanding in an area associated with independent living options and opportunities.

The Center has helped me to learn about:

Yes	No	
☐	☐	Educational and training opportunities
☐	☐	Employment options and opportunities
☐	☐	Affirmative action and fair employment practices
☐	☐	Benefit programs and financial assistance opportunities and how to acquire them
☐	☐	Housing options and/or home accessibility
☐	☐	Personal health and medical issues
☐	☐	Personal care assistance (attendants, housekeepers, etc/) and/or sources
☐	☐	Equipment options and/or aids and how to acquire them
☐	☐	Available social/recreational activities and how to participate in them
☐	☐	Transportation and/or vehicle options and how use or acquire them
☐	☐	Other (WHAT KNOWLEDGE?) ______________________
☐	☐	None

41. Is there anything we haven't mentioned that you feel is important for us to know about the IL Center?

____

____

____

THANK YOU for helping us in our study of Independent Living services. Your help in this study is an important part of the national effort to provide better programs for individuals with disabilities. Please use the enclosed pre-stamped self-addressed envelope and return this survey **IMMEDIATELY** to:

Independent Living Evaluation Project
Berkeley Planning Associates
3200 Adeline Street
Berkeley, CA 94703

OMB Approval No. 1820-0531 B-31 BPAID __________
Expiration Date: 2/86

COMMUNITY AGENCY SURVEY*

Name and Title: ____

Organization Name: ____

Address: ____

______________________________ Phone: ______________________________

The following questions ask for information about your experience and relationship with ______________________________ (Center):

1. What type of agency or organization are you? [CHECK ONLY ONE]

Check Only One

☐ Vocational Rehabilitation Agency
☐ Rehabilitation Facility
☐ Mental Retardation/ Mental Health Agency
☐ Special Education Agency/ Program
☐ Social Security Administration
☐ Welfare Agency
☐ Primary Care Facility (e.g., hospital, nursing home)
☐ Doctor or Other Medical Care Provider
☐ Housing Agency
☐ Employment Service Provider
☐ Transportation Agency
☐ Religious Organization
☐ Business/Corporation
☐ Other (SPECIFY) ______________
____
____

2. What is your relationship with the Center? [CHECK ALL THAT APPLY]

Check All That Apply

☐ We have no specific relationship [GO TO QUESTION 3]
☐ We receive client referrals from them
☐ We refer our clients to them
☐ We work cooperatively to provide coordinated services to consumers
☐ We coordinate with them on community education or advocacy efforts
☐ They provide us with information or technical assistance
☐ We provide them with information or technical assistance
☐ We provide them with funding or other types of support to operate their program
☐ We purchase specific services from them
☐ Other (SPECIFY) ______________________________
____

*____Check if you would prefer that the Center be allowed to see this questionnaire. Otherwise, all responses will be held in strictest confidence.

3. How would you characterize the quality of Center staff with whom you have had contact? [CIRCLE ONE NUMBER FOR EACH ITEM]

Circle One Number for Each Item

	Less				More
Effectiveness	1	2	3	4	5
Responsiveness	1	2	3	4	5
Cooperativeness	1	2	3	4	5

☐ I have not had enough contact to respond to this question.

4. What is your overall assessment of the quality of the services/activities conducted by the Center? [CHECK ONLY ONE]

Check Only One

☐ Poor ☐ Fair ☐ Satisfactory ☐ Very Good ☐ Outstanding

5. From your experience, which of the following describe important aspects of the Center? [RATE THE FOLLOWING BY CIRCLING THE APPROPRIATE RATING]

Circle One Number for Each Item

	Not an Emphasis				Major Emphasis
Provision of services to a range of disability groups	1	2	3	4	5
Peer role models and peer relationships	1	2	3	4	5
Equal access to society by consumers	1	2	3	4	5
Self-help and self-advocacy for consumers	1	2	3	4	5
Equal access by consumers to programs and physical facilities	1	2	3	4	5
Meeting the specific independent living needs of the local community	1	2	3	4	5
Consumers control their own service delivery	1	2	3	4	5
Consumers define their own IL service objectives	1	2	3	4	5
Individuals with disabilities in key staff roles	1	2	3	4	5
Management of Center operations by person with disabilities	1	2	3	4	5
Establishment of Center service priorities by persons with disabilities	1	2	3	4	5
Policy direction by persons with disabilities	1	2	3	4	5
Other (SPECIFY) ____________________	1	2	3	4	5

6. Has contact with the Center caused any changes within your organization? [CHECK ALL THAT APPLY]

Check All That Apply

☐ No changes

☐ Increased our efforts to create options for persons with disabilities

☐ Caused us to make our facility more accessible to persons with disabilities

☐ Changed staff attitudes toward persons with disabilities

☐ Changed our service approaches to persons with disabilities

☐ Increased the job accommodations we make for staff with disabilities

☐ Other (SPECIFY) ____________________

7. Below are listed a variety of community resource areas where the Center may have helped to expand options for persons with disabilities. In your opinion, how much impact has the Center had on the availability and/or quality of options in these areas? [CIRCLE ONE NUMBER FOR EACH ITEM]

Circle One Number for Each Item

	No Impact	Some Impact	Substantial Impact	Not a Goal of Center	Don't Know
Housing	1	2	3	8	9
Transportation	1	2	3	8	9
Personal Care Services	1	2	3	8	9
Education	1	2	3	8	9
Employment	1	2	3	8	9
Communication	1	2	3	8	9
Reduced Architectural and Social Barriers	1	2	3	8	9
Disability Awareness and Social Acceptance	1	2	3	8	9
Recreation	1	2	3	8	9
Physical and Mental Health Care	1	2	3	8	9
Consumer Involvement in Community Affairs	1	2	3	8	9
Legal Services	1	2	3	8	9
Other (SPECIFY) ________________	1	2	3	8	9

8. What outcomes have you achieved with the Center? [CHECK ALL THAT APPLY]

Check All That Apply

☐ Improved services for your clients

☐ Cooperative service agreements

☐ Elimination of service duplication

☐ Sharing of service responsibility and resources

☐ Services to more people

☐ Organized cooperative groups/coalitions to improve options for persons with disabilities

☐ No outcomes achieved

☐ Other (SPECIFY) ____

9. How would you assess the Center's leadership role in the community? [RATE THE FOLLOWING BY CIRCLING THE APPROPRIATE RATING]

Circle One Number for Each Item

	Poor				Out-standing	Not Emphasized by This Center
Effective advocate for persons with disabilities	1	2	3	4	5	8
Influences improvement in services and/or cooperation across agencies	1	2	3	4	5	8
Catalyst for actual changes in the community	1	2	3	4	5	8
Other (SPECIFY) ______________________	1	2	3	4	5	8
______________________	1	2	3	4	5	8

☐ I have not had enough contact to allow me to answer this question

10. Are there services for disabled individuals provided by the Center that are not available from other agencies?

☐ Yes ☐ No

If yes, what are they?

____

____

____

11. Are there any other aspects of the Center or its impacts that you think would be helpful for us to know?

____

____

____

____

____

____

____

____

____

THANK YOU for your participation in this study. Please return this questionnaire in the enclosed prestamped envelope **IMMEDIATELY** to:

Independent Living Evaluation Project
Berkeley Planning Associates
3200 Adeline Street
Berkeley, CA 94703

SITE VISIT DISCUSSION TOPICS

OVERVIEW AND MANAGEMENT

(For discussion with Executive Director and/or Board President)

1. Clarification of mail survey responses to Questions #1 and #5 (history)
2. Distinguishing characteristics of Center.
3. Clarification of mail survey responses to Questions #6 and #7 (target population).
4. Other characteristics of target population.
5. Clarification of mail survey responses to Questions #8, #9, and #10 (philosophy and consumer participation).
6. Other aspects of Center philosophy.
7. Other evidence of consumer involvement/control.
8. Composition and role of Board.
9. Clarification of mail survey responses to Question #11 (organizational and personnel management).
10. Affirmative action procedures.
11. Observation of Center operations and facilities.

COMMUNITY ACTIVITIES

(For discussion with Executive Director, Director of Community Development, related staff and/or representatives of other community agencies)

12. Clarification of mail survey responses to Questions #13, #15, and #16 (community activities and relationships).
13. Description of community activities.
14. Differences between Center activities and those of other agencies.
15. Clarification of mail survey responses to Questions #19, #20 and #21 (impacts).
16. Other areas of impact.

CONSUMER SERVICES

(For discussion with Director of Client Services, service providers and/or consumers)

17. Clarification of mail survey responses to Question #12 (consumers served).

18. Efforts to reach specific disability groups.

19. Eligibility requirements.

20. Clarification of mail survey responses to Questions #14 and #17 (services provided).

21. Process for deciding consumer service package.

22. Clarification of mail survey Question #8 (service philosophy).

23. Description of case management systems.

24. Center definition of core services.

25. Clarification of mail survey responses to Question #18 (impacts).

26. Other types of consumer impacts.

CENTER RECORDS

(For discussion with Executive Director, Director of Client Services, and/or other staff knowledgeable about records)

27. Clarification of mail survey responses to Questions #11, #12, #14, #18, and #19 (client, service and outcome data and record systems).

28. Description of client and service record system.

29. Methods for recording information and referral.

30. Methods for recording community activities.

31. Examples of Center service and evaluation reports.

32. Observation of overall recordkeeping and evaluation procedures.

FISCAL

(For discussion with Executive Director, Fiscal Manager, Bookkeeper and/or Resource Developer)

33. Clarification of mail survey responses to Questions #2, #3, #4 and #5 (funding).

34. Description of Center resource development goals and activities.

35. Clarification of mail survey responses to Question #11 (fiscal procedures).

36. Responsibility for fiscal systems.

37. Observation of overall fiscal system performance.

APPENDIX C

STUDY METHODOLOGY

APPENDIX C

STUDY METHODOLOGY

INTRODUCTION

Congress called for the comprehensive evaluation of the Title VII Part B Centers for Independent Living Program to be conducted based on evaluation standards focused on measuring the outcomes and impacts of the centers. The purposes of the standards were both to be the bases of:

(1) the national program evaluation, to be submitted to Congress in 1986, and
(2) center self-evaluation.

In addition, it was expected that the standards and their evaluation findings might be used for ongoing program evaluation, for selection criteria in future funding reviews, or for specification of center reports.

During the first nine months of the project, the study team, working closely with a national Advisory Panel, (1) developed proposed standards for evaluating the Independent Living Center program, (2) secured a range of review and comment, (3) obtained approval from the National Council on the Handicapped (NCH) and the Rehabilitation Services Administration (RSA), (4) prepared the standards for publication, and (5) developed a detailed study design to guide the activities of the second phase of the project. These five activities involved the synthesis of previous standards development and independent living evaluation efforts. They also involved input of independent living centers, vocational rehabilitation (VR) agencies, and other rehabilitation researchers and knowledgeable individuals around the country.

Standards were distributed to over 500 reviewers nationally, revised, reviewed with the Project Advisory Committee, revised again, reviewed and revised by the Commissioner of RSA, submitted by RSA to the

National Council on the Handicapped, and finally reviewed, revised, and approved by NCH as of January 1985.

Simultaneously with the extended review process for the standards, the study team developed three survey instruments and a study design to collect evaluation. The data were to be used to determine center compliance with the standards and to provide information addressing the various questions raised by Congress to RSA. Questionnaire instruments and the study design were reviewed with the project Advisory Committee, and the questionnaires were pretested in six sites and with nine disabled consumers. Based on the pretest, refinements were made and the design was submitted for OMB review. Site visit and mail survey data were collected and analyzed as described below.

DATA COLLECTION APPROACH

To address the variety of study design issues outlined in the standards, a multi-faceted data collection approach was used. The study combined information from centers themselves, from consumers of center services, and from community organizations. For each of these three target respondent groups, information was collected by on-site or phone interviews and by mail survey.

(1) On-site and Phone Interviews at 40 centers with administrators, staff, consumers, and community organizations were undertaken to obtain in-depth information. Semi-structured interviews and primarily open-ended questions were used in these interviews.

(2) Mail surveys were undertaken with 156 centers, 2,700 consumers and 180 community organizations.

Table C-1 presents a matrix showing how information from each source was used to address the study questions. Where a "P" has been entered, that instrument/target was a primary source of information; where an "X" has been entered, the source was secondary. The survey and site visit instruments used for collecting the data are included in Appendix B.

Table C-1

Information By Instrument Matrix

	Data Sources						
	Centers			Consumers		Community Organizations	
	Mail Survey	Site Visits		Telephone/ Face-to-Face	Mail Survey	Telephone/ Face-to-Face	Mail Survey
		Pretest	Other				
Categories of Information	N = 156	N = 6	N = 34	N = 80	N = 2700	N = 40	N = 180
PROGRAM							
Implementation	P	X	X		X	X	X
Interrelationships	P	X	X			X	X
Philosophy	P	P	P	X	X	X	X
Funding Support	P	X	X	X		X	X
Evaluation Standards	X	P	P			X	X
CENTER OUTCOMES (IMPACTS)							
Consumer Outcomes	X	X	X	X	P	X	X
Community Outcomes	X	X	X			P	P
Best Practice	P	P	P	X	P	X	X
CENTER SERVICES							
Consumer Services	P	X	X	P	P		
Outreach/Community	P	X	X			P	P
Consumer Involvement	X	P	P	P	P	X	X
Clients Served	P	X	X	X	P		
Communities Served	P	X	X			P	P
ORGANIZATION/ADMINISTRATION							
Decison-Making	P	P	P		X		X
Staffing	P	P	P		X		X
Policies and Procedures	P	P	P		X		X
Funding Support	P	P	P		X		X

P = primary data source; X = secondary data source

The administration of the mail survey involved the following procedures:

- mail questionnaires to all centers, related community organizations, and consumers according to the sampling plan (described in the next section;
- accompany the questionnaire with a letter stressing the importance of the survey and urging rapid completion and return of all questionnaires;
- make three complete rounds of phone calls to nonresponding centers;
- follow phone calls with a letter from the National Council on the Handicapped asking centers to complete the survey if they had not already done so; and
- make follow-up calls to a sample of nonresponding consumers (one-third of the nonresponding consumers from two-thirds of the sample centers).

SAMPLE SELECTION

Center Samples

Center Mail Survey Sample

The center mail survey included the universe of 156 centers in the Part B program. (The original listing used contained 164 entries. However, in several cases, programs listed were in fact satellite offices of a center and responses to the survey combined data across center sites.) Consequently for this survey there was no requirement for a statistical sampling process. As of the time of this report, 121 centers had responded (78%).

In order to determine if any response bias existed, information was collected about 22 nonresponding centers. The 22-center nonrespondent group was very similar to the respondent group in terms of independent agency status (59% for both samples), consumers seen per month (mean of 54 for nonrespondents versus 43 for respondents), for the number of paid staff (9 versus 11), and total amount of Part B funding ($280,000 versus $323,000). The nonrespondent group was somewhat more likely to have Boards with a majority of disabled individuals than was the respondent sample (68% versus 55% of centers), although the difference was relatively small. This comparison suggests that the 121-center sample used in the analyses is representative of the overall universe.

A final piece of evidence in support of the representativeness of the 121-center sample is that the 121 centers comprise almost the same percentages of both the overall number of centers and also of the overall Part B funding for the program nationally. That is, the Part B funding received in aggregate by the centers is about 81% of the total program Part B funding, and the center sample comprises 78% of the total number of centers.

Site Visit Sample

The selection of sites to be included in the 40-site sample was a two-step process. First, early in the study, six centers were selected to pretest the data collection instruments. These centers were selected to represent a range of different types in order to test the appropriateness of the instruments across different sizes, organizational configurations, and centers with different types of target populations.

The remaining centers were selected randomly from the universe of Title VII Part B centers. The profile characteristics of the random sample were compared to information about the universe of centers collected through phone discussions with regional RSA staff, to ensure that a representative sample was chosen. Pretest sites that did not appear in the sample resulting from the random sampling process were not included in the consumer and community mail survey data collection activities, in order to ensure that the consumer and community agency populations would also be truly randomly selected.

Consumer Sample

The sample for the consumer mail survey was selected from the randomly chosen sample centers. In order to obtain a sufficient sample of individuals to make comparisons across centers and across subgroups (male versus female, disability type, etc.), we surveyed 100% of the consumers served in the smallest centers. A minimum sample size of 80 respondents per center was set, and for larger centers, 40% of consumers (up to 150 respondents) were mailed questionnaires. This resulted in a total sample of 2,700.

In cases where centers kept unduplicated records of individual consumers served for a service year or other service period, a simple systematic random sampling procedure was followed, selecting from those served in the most recent month and those served during the month that was six months prior to the recent sample month. Beginning with a random number between one and four, centers selected every nth file, where n equaled the number of consumer records divided by the size of sample desired.

In other centers, records were kept separately for different service components (file for transportation, file for housing, etc.). In these programs, proportional samples were selected from each of the separate record systems; within these subsamples, the systematic random sampling procedure was followed. The resulting sample was scanned for duplicates, and additional sampling was conducted as necessary to replace them.

When necessary, slight variations on the systematic sampling method were individually tailored for each site, based on the arrangement of consumer records. The sampling approach was verified during the site visit. Research staff provided technical assistance to each assigned center by phone during sample selection. The research team worked with the sites both in selecting the consumer sample and in establishing follow-up procedures that respected center assurances of consumer confidentiality.

Most centers sent letters (using a standard format developed by the research team) to sample consumers in advance, notifying them that their name had been selected at random, that a survey from the research team would be forthcoming and that their confidentiality would be protected. No identifying information was included (or asked for) on the survey except for an identification number keyed to a list of addresses and phone numbers used for follow-up. Once follow-up procedures were complete, the lists were destroyed. For one center, follow-up calls were made by the state VR agency using the sampling methods and phone protocol developed by the research team, because the center was unwilling to release identifying information to the contractors.

Our pretest experience suggested that most consumers would be eager to participate in the survey. The major potential cause of nonresponse was likely to be barriers presented by individuals' disabling conditions. The pretests confirmed that the survey worked equally well over the phone or in person (as by mail), should individuals require assistance. Several procedures were adopted to assist completion of the questionnaire by the severely impaired. Extra large check boxes were used on the form, to make the questionnaire more easily used by individuals with motor impairments. For those unable to see or physically complete the form, encouragement was given to the consumer to have a family member or friend fill out the form, but only in direct consultation on each data item with the consumer. A place was provided on the questionnaire to indicate if assistance was used.

Follow-up procedures were conducted to maximize response rates. In brief, these procedures were as follows:

- contact one-third of the nonrespondents by phone three weeks after initial distribution of the surveys;
- mail a second survey instrument to all those requesting them;
- two weeks later, implement a telephone reminder to continued nonrespondents, and, if necessary, conduct the interview over the phone or TDD.

Of the 2,700 questionnaires distributed to consumers, this analysis is based on 990 respondents, a response rate of 37%. An additional 40 responses were received too late to include in the analysis.

A check on the representativeness of the consumer survey respondent sample was made by following up on nonrespondents to see if there was any apparent response bias. Attempts were made by phone to contact one-third of all the nonrespondents at two-thirds of the centers used to draw the consumer mail survey. The total nonrespondent sample ultimately included 333 consumers. After three contact efforts, all but 88 of these nonrespondents had been interviewed, a successful contact rate of 76%. Of those contacted, 81% stated that they were fully willing to participate, and gave explanations for not yet responding, such as misplaced questionnaires, "it's in the mail," etc. (Those who had misplaced the questionnaires were sent a second copy, and potentially may be among the larger consumer sample to be analyzed in the Final Report.) Only 19% of the nonrespondents actually indicated their choice was not to participate.

Among these individuals choosing not to participate, the predominant reason given for this choice was that they had limited contact and knowledge of the center. Among the respondents, 20-30% of consumers were reporting no gains in skills or knowledge, or receipt of aids; 24% reported no situational improvement. Thus, the percentage of nonrespondents (19%) indicating possible limited or nonsuccessful interactions with the centers is, at worst, the same and may even be less than the comparable percentage within the respondent sample. Also, analysis of the nonrespondents indicated no statistically significant differences in types of disabilities represented in the sample.

Community Agency Sample

Ten agencies were nominated by each of the sample centers for inclusion in the survey sample, based on intensity of contact with the center and its consumers. Where the center was not the Part B grantee, the grantee was included among these agencies. The study team selected five of the ten nominees from each center to represent a range of different types of agencies, and those agencies with which the center had the greatest intensity of contact. A total of 180 agencies were included in the survey. This report is based on 100 respondents, for a response rate of 56%.

ANALYSIS

This project provided the opportunity to obtain information of both a quantitative and a qualitative nature. Quantitative analysis has been conducted on most of the information obtained through the mail surveys to centers, consumers and community organizations. The data on those forms were cleaned and coded as forms were returned, and a combined data set was developed for computer-assisted analysis using the Statistical Package for the Social Services (SPSS). Cleaning, coding and data entry were verified for accuracy, and decisions or judgment calls were made by the Project Director to ensure consistency across all the surveys.

Not all information generated through this study was amenable to quantitative analysis. The in-person interviews provided rich contextual and interpretive data such as: information on the history and evolution of specific centers and programs, as described by center personnel and those involved with the center; perceptions of those respondents as to the effectiveness and efficiency of existing procedures, staffing arrangements, and interorganizational relationships; and personal histories, perceptions and attitudes of center consumers While less standardized (and therefore less amenable to tight comparisons or statistical analyses), information of this type was useful in interpreting the statistical analyses, and also for highlighting the subtler nuances of the specific environmental factors (e.g., barriers, unique features of the center, staff and community) which come together to facilitate or inhibit successful operations and impact on the community and disabled persons.

There have been two broad purposes of the research and analysis activities to be conducted in this project. The Congressional questions of Section 171(c)(3) focus to a great extent on the first of these, description. Research for this purpose has been aimed at providing information about what is happening in the program: what kinds of consumers are served with what outcomes? What types of organizations have evolved, providing what services? What impacts on consumers and communities have resulted?

While description is an important objective of this study, an equally important objective is that of explanation; that is, the elucidation of "why" conditions are the way they are, documented through descriptive analysis. In particular, policymakers and those working in the centers would like to understand how different inputs (funds, resources, etc.) and processes (services and activities) lead to better or worse outcomes and impacts. This report provides some of this analysis, but is necessarily limited to exploratory analysis because of the short time frame for completing the report due to Congressional deadlines. The data base compiled, however, is the richest by far to date in the independent living research and program field. It is hoped that it will be exploited through subsequent research to provide insights on the most effective service and organizational strategies for achieving different goals with consumers of differing characteristics.

APPENDIX D

DESCRIPTION OF PERFORMANCE ON INDEPENDENT LIVING CENTER EVALUATION STANDARDS

APPENDIX D

DESCRIPTION OF PERFORMANCE ON INDEPENDENT LIVING CENTER EVALUATION STANDARDS

STANDARD 1: PHILOSOPHY

The center shall promote and practice the following Independent Living Philosophy:

1.1 Consumer control of policy direction and management of the independent living center
1.2 Consumer control of the development of own Independent Living service objectives and services
1.3 Self-help and self-advocacy
1.4 Equal access to society by individuals with disabilities
1.5 Equal access to programs and physical facilities
1.6 Development of peer relationships and peer role models
1.7 Meeting the specific independent living needs of the local community
1.8 A range of services to all people with disabilities

A. Description and Purpose of Standard

The overall purpose of the philosophy standard is to ensure that the intent and key elements of the independent living philosophy are incorporated in the structure, operations, and service approaches of an independent living center. This standard is significant because the independent living program emerged from a strong philosophical orientation that distinguishes it from other programs, an orientation that underscores the fact that persons with severe disabilities can manage their own lives and be active contributing members of society. Inherent in the consumer control and self-help elements of this standard is the belief that consumers can act on their own behalf in achieving their independent living goals. The concept of peer role modeling and peer relationships emphasizes that persons with disabilities who have struggled for independence can best help others trying to cope with that struggle. The peer concept also is frequently linked to the core service of peer counseling and is directly affected by independent living center hiring of staff with disabilities to act as role models.

B. Summary of Achievement

Independent living centers generally stress their philosophical concurrence with all the elements listed in this standard. Community agencies, as well, gave high ratings to the centers in terms of their adherence to this standard, though the ratings were in most cases not as high as the self-reported from the centers. Consumer control over policy, at least as measured by consumer participation in center boards of directors and administration, appears to be quite strong: the average rate of participation by person with disabilities on center boards is 49%, and 51% of center directors are disabled. However, site visit reports indicate that centers varied greatly in their degree of consumer control.

Independent living centers have placed a major emphasis on consumer oriented service concepts associated with consumer control of service objectives and services, self-help and advocacy, and peer role modeling and peer relationships. A majority of consumers also indicated that their experiences with centers reflected these principles, with over 50% of the individuals surveyed reporting they had set their own goals or chosen their own services. A large number of consumers have worked with disabled staff at centers. Urban centers with larger budgets and disabled directors were more likely to have consumers who claimed they controlled their objectives and services. In addition, consumers from free-standing centers with boards that have a majority disabled membership were more likely to report working with disabled staff in a peer relationship.

All of the centers claim they devote at least some time to ensuring their communities are accessible to people with disabilities. Equal access to the centers' own facilities and programs generally has been assured, according to the consumers surveyed. Over 70% reported their center services were accessible as measured by at least one indicator. Finally, independent living centers generally are providing services to a range of disability groups. No one disability group is underrepresented among center consumers when compared to the incidence of disability in a national sample.

C. Findings

Results of the center survey clearly indicate that Standard 1 and its components are highly valued. Independent living centers were asked to rate each philosophical component on a five-point scale (with "1" low and "5" high). The overall mean score for all components was 4.4, and averages for each element ranged from 3.7 to 4.7, as shown in Table D-1-A.

When center administrators were asked during site visits to describe their organizational philosophies, various versions of the standard components were recited. Although descriptions were similar, there was wide variation in the way philosophies were incorporated in day-to-day operations. It should be noted that this is commonly found when new philosophies are put into practice. As a field develops, consensus about accepted practices emerges over time.

Community agencies also rated centers highly on all aspects of independent living philosophy. The average rating on the five-point scale was 4.3, and responses ranged from 3.8 to 4.2.

1. To What Extent do Centers Emphasize the Concept of Consumer Control Over Policy Direction and Management of the Independent Living Centers?

Consumer management had the lowest mean rating (3.7) by the centers as an area of emphasis and the greatest variability across center survey data. The average community agency assessment was slightly higher than centers' own ratings. However, responses show that the average percent of persons with disabilities on center boards of directors is 49%, although there was wide variation: 20% of the centers reported having no board members and another 15% had no board of directors (separate from their umbrella agency. Thus, 35% of the centers had no persons with disabilities in policy-making roles. On the other hand, 3% had boards with 100% disabled members.

Several issues emerged during the site visits regarding board composition. First, centers report difficulty finding consumers to occupy certain important board positions. Centers want consumer input and advocacy on boards, but they also require members who possess

Table D-1-A

Average Center and Community Agency Ratings*

of Standard 1 Components of Independent Living Philosophy

Philosophy component	Average Center Rating	Average Community Agency Rating
Persons with disabilities control the policy direction and management of the center	4.0	3.9
Persons with disabilities establish Center service priorities	4.2	3.8
Persons with disabilities manage Center operations	3.7	3.7
Persons with disabilities serve in important staff roles	4.3	4.0
Consumers control the development of their own IL service objectives and services	4.3	3.7
Center encourages consumer self-help and self-advocacy	4.7	4.4
Equal consumer access to Center programs and physical facilities	4.7	4.1
Center encourages peer role models and peer relationships	4.6	4.1
Center works to guarantee equal access to society by individuals with disabilities	4.7	4.2
Center provides a range of services to all peopole with disabilities	4.1	3.9
Center works to meet the specific IL needs of the local community	4.5	4.1

*Based on a rating scale of 1 (not an emphasis) to 5 (strong emphasis).

influence in the community and access to funding and other resources. Because most consumers are less likely to meet the latter requirements, centers often turn to nondisabled persons. Many independent living centers feel that a varied board including individuals with different combinations of skills, experience and influence offers the best approach.

Survey findings indicate that 52% of the centers employ a disabled director. Centers also report some difficulty in finding and attracting highly qualified persons with disabilities for directorships, sometimes resulting in a decision to hire an individual with good qualifications who is nondisabled. Other centers reported that the independent living philosophy requires that an individual have experience with disability (at least with a family member, if not directly) in order to be highly qualified for many of the staff positions needed to effectively run the center. Some proponents feel strongly that personal experience with disability is a necessary prerequisite to being a center director. As emphasized by the center site visit findings, centers often must grapple with the decision of providing training for persons with disabilities who may not initially possess all of the necessary qualifications for the position versus hiring a well-qualified but nondisabled person.

Although a range of practices stemming from this standard exists in the centers, the site visits provided an opportunity to make general observations about these variations. One important observation is that

implementation of independent living philosophy. Board members and administrators must practice the independent living philosophy in their management and decision-making in order to be effective. Their leadership position is essential to ensuring that independent living philosophy carries over to staff and consumers.

2. To What Extent Do Centers Emphasize Consumer-Oriented Service Delivery?

The study examined center-reported emphases on consumer control over service objectives and services, self-help and self-advocacy, and peer role models and peer relationships. Respondents to the consumer survey also reported on the extent to which experiences with centers reflected these concepts, and community agency representatives rated independent living centers on these issues.

Centers claimed a major emphasis on the philosophical concepts associated with consumer-oriented service organization and delivery. The mean rating that centers gave to these concepts exceeded 4.5 in each case. Some deviation occurred in the spread of ratings related to consumer control of service objectives and services, indicating some variation in center emphases.

The findings indicate that a majority of the consumer survey respondents felt that they were responsible for setting their own independent living goals (51%) and were most responsible for choosing their independent living services (55%). There was also evidence that consumers had experienced peer relationships with 21% of the sample indicating that they had worked with a person with a similar disability and 44% reporting they had worked with a person with a different disability.

Consumer respondents also gave high ratings to centers regarding their adherence to independent living service philosophy concepts. As shown in Table D-1-B, mean ratings of service philosophy variables were high in terms of consumer control of goals and services as well as for other concepts associated with an independent living center's commitment to responsive consumer-oriented services.

Community representatives gave high ratings to independent living centers for their emphasis on self-help and self-advocacy (4.2) and provision of peer roles models and peer relationships (4.1). However, their responses indicated less of a belief that the consumers of independent living centers define their own objectives and control their own services (3.8).

The study examined the extent to which an emphasis on consumer oriented service concepts might be influenced by such factors as size (level of funding as well as total number of consumers served); type of independent living center (independent versus part of a larger agency); percentage of staff with disabilities; majority versus non-majority consumer board; type of service locale (urban, rural, etc.); and extent

Table D-1-B

Consumer Assessment of Center Emphasis on Independent Living Philosophy and Service*

Philosophy Component	Mean	Standard Deviation
Helping me get services easily and quickly	4.1	1.21
Helping me get benefits and sevices from other places	4.0	1.31
Allowing me to define my own service goals	4.3	1.11
Allowing me to have control over my services	4.3	1.07
Helping me increase my independence	4.4	1.11
Improving the community for all persons with disabilities	4.2	1.15
Involving disabled people in running the IL Center	4.3	1.13
Establishing a leadership role in the disabled community	4.1	1.27

*Based on a rating scale of 1 (not an emphasis) to 5 (strong emphasis).

to which center was supported by Part B funds (percent of total funding). The findings revealed no significant differences in how centers claimed to emphasize the consumer oriented service concepts associated with independent living.

However, consumers from those centers in an urban setting and with Part B funding as a lower percentage of their overall budgets were significantly more likely to report that they had the largest role in setting their own goals and choosing their own services. In addition, the presence of a disabled director appears to be related to higher levels of consumer service choices, and a larger center budget correlated with more frequent consumer goal setting (these latter two findings are significant at the .2 level only).

The study also found that urban centers with boards that have a majority disabled membership and with higher levels of funding are more likely to have consumers reporting they worked with disabled staff members. Consumers from free-standing independent living centers more frequently indicated they worked with disabled staff (at a significance level of .2), compared to consumers from programs within umbrella agencies.

Site visits also revealed differences in the interpretation and implementation of consumer-oriented concepts such as self-help and peer role modeling. For example, field research highlighted a dilemma tied to the maturation of the independent living service model. As independent living services become better defined, structured, and organized in ways that contribute to a more focused and effective approach, it is possible that the concepts of consumer control and self-help will suffer; i.e., that services will be driven more by the structure and less by the consumer. Also, there is an issue that is emerging in urban centers where, as they become more effective in attracting consumers, they experience backlogs -- consumers on waiting lists. This creates pressure to move consumers more quickly through services to allow other consumers to be served. It becomes more difficult to let the consumer's interest, pace, and way of working dominate the service process.

Some consumers also are able to understand their options and sort through different options and decisions more easily than others.

Because there are significant differences in capabilities among consumers, consumer control is related to the degree of independence and sophistication of the individual consumer.

Site visit reports indicate that peer role modeling and peer relationships are linked to staffing considerations in centers as well as how peer counseling is defined. Peer role modeling can be formalized in the staffing structure, with staff acting as role models, or it can occur through peers (consumers) working with other peers. Those centers that felt the most strongly about peer role modeling as a staffing requirement were those that were most insistent about independent living centers hiring persons with disabilities in key administration positions as well as in direct service positions.

A general observation about the peer role modeling and peer relationships concept is that the overall service design of a center is so closely tied to other aspects of independent living operations that it is difficult to examine this concept separately. It is surely related to the ability to recruit, hire, and maintain qualified competent staff who understand the espoused independent living tenets. This has been difficult in many centers visited where high staff turnover or hiring policies did not result in the maintenance of such staff.

3. To What Extent Do Centers Address Equal Access Issues and Meet the Independent Living Needs of the Local Community?

The study examined the range of independent living center activities to promote equal access to society for all persons with disabilities, and how effectively centers provided equal access to their own programs and physical facilities. In addition, the study attempted to determine if centers meet the specific independent living needs of their particular local communities.

All centers reported that they direct some percentage of their time to community equal access activities, ranging from one center that devoted 1% of its resources to one that allocated 60% to facilitating more options for persons with disabilities in the community. The average percentage of time devoted to these activities was 25%.

Responsibility for organizing community development activities varies. Alternatives include setting up separate community development departments which work with other service staff to bring about needed community changes; assigning overall responsibility to an administrator or director who works with appropriate staff and consumer representatives; assigning community development responsibilities to the staff person responsible for a specific service area, e.g., housing, transportation, or attendant care; retaining major responsibility within the Board of Directors; and relinquishing responsibility to consumer groups. In a few centers, partial acceptance of the independent living philosophy or restrictions imposed by umbrella agencies with different philosophies and strategies limited the extent to which community access was addressed. Center community activities are examined in more detail in Standards 4 and 7.

A higher number of centers claimed they provide equal access to their own programs and facilities than claimed adherence to any other element under Standard 1. The mean response was 4.7, with only seven centers indicating less than "strongly agree" on the survey. In addition, 70% of the consumers surveyed reported that their center was accessible in at least one of four ways: near public transportation that the consumer was able to use; in a building easy to enter and leave; easily reached by phone; or through transportation provided by the center. Only 18% claimed their center was not easy to visit.

However, some barriers to accessibility of center programs still exist. Only 24% of the consumers surveyed stated that their center was close to public transportation they could use. Site observation supports the assessment that public transportation remains a difficult issue for many centers, where the agency may not be able to change its accessibility by public transportation without a significant transformation in the local system at large.

The wide variety of disabilities served by independent living centers, the wide range of center services, and the large degree of variation between centers indicate that centers have established a service environment designed to meet local community needs. Centers claimed they emphasized meeting local needs at an average 4.5 level on a five point scale and community agencies gave an average rating of 4.1 to centers for their efforts. In addition, 94% of the community agencies surveyed reported that centers are providing unique services not available from other agencies in their community.

4. To What Extent Do Centers Provide a Range of Services to All People with Disabilities?

As indicated in Table D-1-A, providing a range of services to all people with disabilities is rated as a strong emphasis by most centers, an average 4.1 of a possible 5 points. However, of the 119 centers that responded, 11 centers indicated disagreement with this aspect of center philosophy, indicating that provision of a range of services to all people with disabilities was not a strong emphasis in those centers. Center-reported concurrence with the goal of serving all disabilities was highly correlated with provision of services to different disability groups. Those centers recording a "4" or "5" on the survey were significantly more likely to have consumers from all six disability groups.

In examining Standard 1 achievement, we looked at the number of centers who serve people from each major disability group. As one might expect, the disability groups that are more traditionally linked to independent living services (e.g., people with visual, hearing, and orthopedic impairments) are served by the highest percentage of centers. Even so, centers are expanding their target populations. About two-thirds (66%) of the centers serve people who are mentally ill and approximately the same percentage (65%) serve mentally retarded consumers. One interesting finding is that the highest percentage of centers (88%) serve people with visual disabilities, although this disability group represents only 15% of the consumers whose disability is known.

In looking at the percentages of consumers served, we were interested in assessing if certain disability groups were under-represented in comparison to their national incidence. Although no data source matched exactly the type of information we have collected, some comparisons can be made by reviewing data from the 1976 Survey of Income and Education (SIE), which provides information on limitations of activity by type of limiting health condition (see Table D-1-C). The SIE respondents are five years of age and older, and each respondent reported on the average 1.4 limiting health conditions. We reported our comparison sample in two ways -- using the percentages of people who report the condition as primary and the combined percentage of consumers who reported a disability as either primary or secondary (containing duplicated counts of disability categories). On the average, consumers surveyed reported 1.5 disabling conditions, a figure similar to the number of health conditions reported per person in the SIE. A comparison of the two groups revealed that no disability group was underrepresented in the consumer sample in comparison to the national sample.

D. Discussion and Conclusions

Standard 1 provides the foundation for all of the ensuing standards. It highlights the necessity of a unique center structure that includes a range of assistive services, consumer control in defining and implementing these services, and an awareness of and active participation in defining local needs and developing community services.

From the accumulated responses from center, community agency, and consumer surveys, it appears that the study has captured the set of philosophical beliefs that the standard needs to encompass. There is an agreement among respondents that the independent living philosophy is important, and that these components establish a framework for the development of goals which will enhance the quality and extent of independent living for consumers with disabilities.

While center commitment to these concepts was high, there were also indications from consumers and community agencies that at times the translation from philosophical principle to practice has not been complete. The variety of ways in which centers have defined these concepts has created organizational differences, particularly as centers become more established and strive to serve a greater number of consumers, causing changes in agency structure and practice.

Table D-1-C

Comparison of Consumer Respondents with National Prevalence of Disability Types

Disability Type	National Prevalence[a]	Consumer Respondents	
		Condition Primary	Condition Present
	%	%	%
Visual Impairment	7.0%	5.9%	22.9%
Hearing Impairment	7.2	3.9	12.2
Orthopedic Impairment	47.7	54.3	72.7
Mental Illness	2.5	2.7	6.2
Mental Retardation	3.0	3.0	5.5
Other	72.0	10.0	28.9
Multiple	--	19.7	--

[a] Based on the Survey of Income and Education, Bureau of the Census, 1976.

STANDARD 2: TARGET POPULATION

The Center shall have a clearly defined target population that includes a range of disabilities.

A. Description and Purpose of Standard

This standard is best understood in the context of other standards. For example, Standard 1.8 states that centers should provide a range of services to "all people with disabilities." Standard 5 requires certain core services (advocacy, independent living skills training, peer counseling) be provided to individuals within the center's target population, and Standard 6 requires that centers provide information and referral services to all enquirers, even those outside of the center's target population. In combination, these standards work together to ensure that centers target a range of disability groups and provide a minimum of information and referral to all disabled individuals regardless of type of disability, while still offering centers some flexibility in determining specifically what groups to target. This flexibility is consistent with Standard 1.7 which requires centers to respond to the needs of their local community in which some groups may be more in need of independent living services than others depending on availability of other types of services.

It is also the intent of this standard that centers organize their services around clearly defined target populations. Historically, many centers have maintained unique definitions of who is eligible for their services. In some cases the target population may legitimately be "all people with disabilities" and a center may choose not to be more restrictve than that. However, even these broad-reaching centers can benefit from a periodic reexamination of their intended target groups and identification of priority targets as local needs shift over time.

B. Summary of Achievement

Independent living centers are serving people with a wide range of disabilities, many of whom are severely disabled. Although, as might be expected, those individuals with orthopedic impairments predominate among the consumer population, centers are serving many with other kinds of primary disabilities. According to one indicator -- receipt of SSI or SSDI -- over half (57%) of the consumers surveyed among 36 sample centers are severely disabled, while another indicator shows that two-thirds (75%) of the consumers can be considered severely disabled.

The individuals in the study's consumer sample are largely white and of low economic status. More than two-thirds (70%) are currently or have been vocational rehabilitation clients, and half (53%) do not live in their own homes. There are some statistically significant differences between those consumers who seek center assistance primarily to increase their independence and those who are trying to maintain current levels of independence. "Gain" clients tend to be younger and more frequently receive certain kinds of services at the center itself. Maintenance clients generally became disabled after the age of 22. About 13% of centers' consumers resided in institutions at the time of their first contact with the center, indicating that at least some centers are targeting an institutionalized population for services.

A large majority (59%) of independent living centers are setting specific objectives for types and numbers of disabilities to be served. Nearly half (49%) are serving a broad range of disabilities, and nearly all (88%) target more than one disability group. Free-standing centers are significantly more likely to serve a wider range of disabilities. Single-disability centers tend to concentrate on individuals with visual impairments. Site visits revealed that centers employ a variety of processes and sets of criteria to determine consumer eligibility for services, and that these decisions sometimes are influenced by the center's funding agency or an umbrella agency. One issue that many centers are confronting is whether to serve all those who request assistance or to target particular groups of people that may not be able to initiate contact with an independent living center on their own.

C. Description of the Target Population

The primary source of descriptive information about consumers is the consumer survey administered to clients from 36 sample centers. All of the information reported here is from this source except for much of the disability data, which is from the center mail survey.

1. Type and Severity of Disability

Of the total number of consumers served across the 121 responding centers (N=111,560) centers reported information about disabilities for approximately 62,100 people, or 56% of their consumers. Of these, some 13,800 were identified as not disabled (e.g., friends, parents, spouses). The 48,300 consumers for whom disability information is known represent a large majority of the consumers who received direct services from the centers. For 49,700 consumers (44%) disability information is unknown; these consumers are primarily those who have received Information and Referral services from the center and for whom case files were not opened.

As Table D-2-A illustrates, the most commonly targeted population across centers is consumers with orthopedic disabilities. Approximately 48% of consumers for whom disability information is available experienced mobility impairments such as spinal cord injuries, amputation or absence of limbs, polio, multiple sclerosis, arthritis, and cerebral palsy. This relatively high percentage is not surprising, given the centers' historical emphasis on serving people with mobility impairments. What is perhaps more surprising is that so many of the consumers served by the centers do not have orthopedic impairments as their primary disability. The second most frequently targeted population is individuals with hearing impairments, 91% of whom were reported as deaf. "Other disabilities," represents a range of disabilities such as diabetes, epilepsy, stroke, and head injuries. The mentally ill and the mentally retarded are the least targeted populations, although 63% and 64% of centers, respectively, serve some individuals with these disabilities (see Table D-2-B).

A majority of consumers became disabled prior to adulthood -- before the age of 22. As Table D-2-A demonstrates, 29% of those served have been disabled since birth and an equal percentage became disabled as children, adolescents, or young adults.

Table D-2-A

Type and Severity of Disability

Disability Category	#	Disability Known % N=48,063	Total Clients Served (Including I&R) % N=111,560
Visual	5,676	11.8%	5.1%
Hearing	8,146	16.9	9.6
Orthopedic	23,964	47.8	20.6
Mental Illness	2,300	4.8	2.1
Mental Retardation	1,565	3.3	1.4
Other	7,412	15.4	6.6
Disability Unknown	49,700	----	44.6
Not Disabled	13,797	----	12.4
Total	111,560	100.0%	100.0%

Age at Onset of Disability	#	%
At Birth	266	29.1
Under 22	268	29.3
22 or Over	380	41.6
Total	914	100.0%

Types of Mobility Aids	Use Aid, N=951	
	#	%
Electric Wheelchair	252	26.5%
Manual Wheelchair	451	47.4
Walker	135	14.2
Crutches or Walking Cane	192	20.2
Seeing Eye Dog	4	.4
White Cane	45	4.7
Other Mobility Aid	76	8.0
No Aid Used	231	24.3

Types of Consumer Assistance	Receive Assistance, N=939	
	#	%
Attendant	359	38.2%
Reader	91	9.7
Interpretor	52	5.5
Housekeeper	299	31.8
Other Personal Helper	256	27.3
None Used	274	29.2

Table D-2-B

Number of Centers Serving Specific Disability Groups

Disability Group	Centers Serving This Disability Category (N = 112) #	%
Visual Disabilities	98	87.5%
Hearing Disabilities	92	82.1
Orthopedic Disabilities	96	85.7
Mental Illness	74	66.1
Mental Retardation	73	65.2
Other Disabilities	89	79.5

The use of mobility aids by consumers is also shown in Table D-2-A. Because some consumers use more than one aid, the total frequencies exceed 100%. A striking finding is that 76% of consumers report the use of some type of mobility aid. Unduplicated counts were obtained through analysis for the two most frequently used mobility aids, electric wheelchair and manual wheelchair. One hundred clients use only an electric wheelchair and 299 clients use only a manual wheelchair. The unduplicated total of those using an electric or manual wheelchair is 551 or 58% of consumers.

We were also interested in the extent to which consumers required assistance to carry out daily living tasks. As Table D-2-A shows, over 70% regularly use some form of assistance. Use of an attendant was the most frequently cited form of assistance and one that implies a substantial limitation in ability to carry out daily tasks.

Several indicators were used to estimate the number of severely disabled consumers. First, 57% of consumers receive either SSI or SSDI, one indication of the presence of a severe disability. Second, 75% of the consumers responded to at least one of the following severity indicators -- major disability of blindness or use of an electric wheelchair, manual wheelchair, seeing eye dog, white cane, or an attendant. While these are both only estimates, they do indicate that the large majority of consumers targeted by the centers experience major restrictions in work activity, mobility, and performance of daily living tasks.

2. Additional Demographic Information

Chapter III of this report presents the demographic characteristics of the consumers surveyed for this study, including ethnicity, educational attainment, income levels ans sources, vocational rehabilitation client status, and living arrangements. However, Table D-2-C summarizes these basic demographic descriptors as well.

3. Profile of "Maintenance" versus "Gain" Consumers

One of the Congressional evaluation questions is the extent to which independent living services contribute to the maintenance or the increased independence of consumers. Consumers were asked whether the

Table D-2-C

Consumer Demographic Information

	#	%
Sex		
Male	453	46.2%
Female	528	53.8
Total	981	100.0%
Race/Ethnicity		
White	768	78.4%
Black	69	7.0
Hispanic	56	5.7
Asian	9	.9
Native American	55	5.6
Other	22	2.2
Total	979	100.0%
Age		
Under 21	54	5.5%
21 to 40	504	51.5
41 to 60	281	28.7
61 and over	140	14.3
Total	979	100.0%
Monthly Income - at time of first contact with center		
Less than $199	96	22.2%
$200 to $399	155	35.8
$400 to $599	92	21.2
$600 to $799	29	6.7
$800 to $999	25	5.8
$1,000 to $1,999	25	5.8
Over $2,000/month	11	2.5
Total	433	100.0%
	#[a]	% N=847
Source of Income - at time of first contact with center		
Earnings	158	18.7%
Support from Family	206	24.3
SSI	291	34.4
SSDI	190	22.4
Social Security	255	30.1
AFDC	36	4.3
Personal Care/Attendant	58	6.8
General Assistance	79	9.3
Worker's Compensation	14	1.7
Veteran's Benefits	42	5.0
Insurance Benefits	60	7.1
Housing Subsidy	51	6.0
Pension	45	5.3
Alimony	10	1.2
Other	38	4.5

[a] Total exceeds 100% since many consumers have more than one income source.

Table D-2-C (continued)

	#	%
Level of Education - at time of first contact with center		
Less than 9th Grade	85	19.0%
Some High School	67	15.0
Finished High School	135	30.2
Some College	103	23.0
College Degree	28	6.3
Some Graduate Work	22	4.9
Graduate Degree	—	--
Total	447	100.0%
Vocational Rehabilitation Status		
VR Client Now	290	30.7%
VR Client Before	367	38.8
Never VR Client	216	22.9
Don't Know	72	7.6
Total	945	100.0%
Living Arrangement - at time of contact with center		
Institution/Primary Care Facility	107	13.2%
Parent's Home	236	29.1
Supervised Residence	21	2.6
Transitional or Independent Living Residence	13	1.6
Cooperative or Shared Residence	30	3.7
In Own Apartment or Home	374	46.1
Other	30	3.7
Total	811	100.0%

major purpose for using center services was to increase their independence or maintain current levels of independence. Nearly one-third (32%) identified themselves as "gain" consumers, 38% reported they were trying to maintain independence, and the remainder were seeking information or had other purposes.

Correlation of these goal groups with a number of other characteristics shows "maintenance" and "gain" consumers differ in some significant ways. Table D-2-D describes these relationships in detail. A third category includes those individuals who reported contacting a center primarily for information and other reasons. First, Table D-2-D shows that, not surprisingly, gain clients tend to be younger than maintenance clients. Younger disabled individuals are more likely to develop goals for changing their life situations in employment, housing, education, and other areas than older consumers. Second, those people who became disabled after they reached the age of 22 are more likely to fall under the "maintenance" or "other" category rather than the "gain" grouping. Again, because individuals who are disabled later in life generally are trying to preserve the independent status they've already achieved, this finding is not surprising. These individuals usually are already living on their own, have completed their education, and may be employed.

Consumers seeking to increase their independence are more likely to receive their services at an independent living center, as opposed to at home or by phone, in contrast to maintenance consumers. Gain clients require a greater intensity of service generally more readily available at the center, itself. Finally, consistent with the above finding, a greater proportion of gain clients receive independent living skills training, housing, and transportation services. Other services were also found to be significantly correlated with clients' major purpose. For example, receipt of vocational services, educational services, and personal assistance services all revealed significant differences betweeen maintenance and gain clients. As would be expected, proportionately more gain clients received vocational and educational services, and a greater percentage of maintenance clients used personal assistance services. Chapter III presents additional analysis of the

Table D-2-D

Maintenance versus Gain Clients

	Gain Clients		Maintenance Clients		Others	
	#	%	#	%	#	%
Age Group**						
Under 21	29	7.7%	6	1.7%	17	9.2%
21-40	225	59.7	156	45.2	83	44.9
41-60	84	22.3	120	34.8	63	34.1
61+	39	10.3	63	18.3	22	11.9
Total	377	100.0%	345	100.0%	185	100.0%
Age: Disability Onset**						
At Birth	125	35.3%	73	22.5%	49	28.2%
Under 22	105	29.7	95	29.2	53	30.5
22+	124	35.0	157	48.3	72	41.4
Total	354	100.0%	325	100.0%	174	100.0%
Where Services Received**						
At Center	151	42.4%	78	23.5%	67	37.6%
By Phone	83	23.3	103	31.0	62	34.8
At Home	110	30.9	141	42.5	48	27.0
Other	12	3.4	10	3.0	1	.6
Total	356	100.0%	332	100.0%	178	100.0%
Services Received						
ILS**	168	45.4%	83	24.3%	21	11.7%
Housing**	127	34.3	81	23.7	44	24.6
Transportation**	121	32.7	99	28.9	40	22.3
Education**	73	19.7	40	11.7	14	7.8
Vocational**	66	17.8	36	10.5	16	8.9
Personal Assistance**	103	27.8	144	42.1	29	16.2

*Relationship between independent and dependent variable significant at the .05 level

**Relationship between independent and dependent variable significant at the .01 level differences in outcome achievement among maintenance and gain clients.

D. Findings

Over half of the centers (59%) responding to the center mail survey reported their planning process includes specifying objectives for numbers and types of disabilities to be served. While this is not the only procedure that can be used to specify target populations, it does indicate that at least a majority of the centers are targeting their services to certain disability groups. The study examined if specific characteristics of centers, such as free-standing versus umbrella organizational types; percent of budget comprised of Part B funds; percent of board disabled; and the method of receipt of federal funds, influenced whether or not a center had specific objectives for numbers and types of disabilities served. None of the above factors proved to be a significant factor in the practice of this procedure.

One way of determining whether the independent living centers are providing services to people with a range of disabilities is to look at the disability groupings of the consumers served. Slightly under 50% of the centers served consumers from each of six major disability groups, and 88% of the centers served more than one disability group (see Table D-2-E). Only thirteen centers (11%) target their services to people in only one major disability group.

A number of center characteristics -- grantee status, percentage of Part B funding, percentage of board disabled, and number of direct service clients -- had no significant effect on the number of disability groups served. However, free-standing centers are significantly more likely to serve a broader range of disability groups than centers within an umbrella agency. As Table D-2-E shows, these latter centers are, in particular, more likely to serve a single disability group exclusively. The large majority of the single disability centers serve visually impaired individuals; others serve mentally ill or heavily impaired people only.

Information about centers' eligibility criteria collected during site visits revealed that there is no single eligibility process employed by centers. Some centers use consumer-reported disability as the

Table D-2-E

Number of Disability Groups Served by Type of Agency*

	All Centers		Independent ILC		Within Umbrella Agency	
	#	%	#	%	#	%
Number of Groups Served						
1 Disability	13	10.7%	3	4.5%	10	22.2%
2 to 5 Disabilities	44	39.3	28	42.4	15	33.3
All 6 Disability Groups	55	49.1	35	53.0	20	44.4
Total	112	100.0%	66	100.0%	45	100.0%

*Relationship between the independent and dependent variable significant at the .05 level.

method of determining eligibility, while others require medical proof of a disabling condition. Needs assessments sometimes are used by centers to screen potential consumers; a few centers report conducting assessments to determine a person's ability to benefit from the services provided. Several centers require an ability to reach independence with the assistance of their services to reach eligibility, and at least one center strictly complied with this criterion. Although the survey data indicates most centers serve consumers with a range of disabilities, some centers do screen for specific types of disabilities and limit services accordingly. Others may tend to serve a range, but screen out certain populations (such as the chronically mentally ill).

Target population decisions are sometimes made by the umbrella agency of a center, with the center serving a population similar to that of the umbrella. Another factor that influences the type of clients centers serve is funding agency requirements. For example, some centers may focus on vocational rehabilitation clients because of requirements established by that agency.

An important target population issue for centers is the tension between trying to serve all consumers who request services versus targeting services to particular groups. Centers that serve all people who request services may find that they are serving individuals with temporary or less severe disabilities. They will also tend to serve those who are already out in the community, with sufficient independence to initiate contact on their own. However, meeting the demands of these consumers may preclude outreach to institutionalized individuals. There are also monetary considerations that centers face when including deinstitutionalization as one of their objectives. If number of clients served is a main funding or evaluation criterion, centers may be compelled to serve the greatest number of clients instead of those most in need of center services.

Some centers that were very specific about their target population goals did not serve people with a range of disabilities; other centers served people with a wide range of disabilities, but had not clearly defined their target population. Although both these approaches may work for the individual centers, certain issues emerge when one considers the centers' relationship to the communities they serve. If a center serves only a single disability group, other disabled people in the center's service area may not have independent living services available to them. Likewise, centers that don't define a target population for at least some of their services may be caught in a demand-response situation that precludes their ability to engage effectively in outreach efforts or to target services to the most severely disabled.

A service configuration used by some centers and one which is encouraged in the standards, is targeting direct services to specific disability groups while providing Information and Referral services to all who request it. For centers that cover large geographical areas, this is one way to meet service demands.

STANDARD 3: CONSUMER OUTCOMES

The center shall increase individual consumer achievement of Independent Living goals, in areas such as, but not limited to, the following:

3.1 Housing
3.2 Living arrangements
3.3 Income and financial management
3.4 Transportation
3.5 Personal care
3.6 Nutrition
3.7 Household management
3.8 Mobility
3.9 Health and health care
3.10 Assistive devices
3.11 Education
3.12 Employment
3.13 Community involvement
3.14 Family life
3.15 Recreation
3.16 Personal growth
3.17 Social skills
3.18 Communication skills
3.19 Self-direction
3.20 Consumer and legal rights

A. Description and Purpose of Standard

The consumer achievement standard emphasizes that the primary purpose of independent living centers is to contribute to disabled individuals' achievement of independent living goals. The standard lists 20 goal areas that directly relate to living full and productive lives in society, including living arrangements, finances, mobility, and transportation. Standard 3 holds centers accountable for supporting the achievement of consumer goals in these areas. It represents a departure from traditional center data collection and reporting which has focused primarily on process measures, such as numbers of individuals served and services provided, by focusing on the outcomes of these services.

Standard 3 reflects an attempt to identify a common set of types of consumer goals in order to capture outcomes across centers. An alternative approach would be to measure achievement of individual consumer goals, which may vary widely with disparate client objectives and capabilities, and with the broad range of center program emphases. In fact, several centers indicated "number of goals achieved" as an alternative outcome measure. However, while this strategy does reflect more closely the extent of variation among centers and consumers, it would make aggregation or analysis across centers or consumers extremely problematic. By selecting a set of common goal areas critical to the overall achievement of enhanced independent living, Standard 3 permits comparisons among centers and consumers, as well as further refinement of a set of appropriate independent living outcomes for centers and consumers to work towards.

B. Summary of Achievement

The evaluation measured consumer achievement as reported by all centers responding to the center mail survey and by consumers from 36 sample sites. Centers reported more than 58,000 outcomes across 15 areas; the most frequently reported achievement was securing services for consumers through referral to other programs. Almost 75% of the consumer respondents reported at least one gain in housing, education, employment, income, or transportation while in contact with an independent living center, and 69% reported a more independent housing situation (the area with the greatest gains). Approximately 90% of the consumers stated they had made at least one gain related to four additional areas probed by the study: personal and social changes; increased knowledge of the type likely to facilitate independent living; increased skills in meeting their own needs; and the receipt of aids, benefits, and services. The most frequently reported achievements were within the personal/social change cluster.

Bivariate anlayses showed that only age and VR status -- of the consumer characteristics tested -- were statistically significant in relation to consumer-reported outcomes. The nature of the consumer's contact with a center -- the frequency, location, and type of services received -- appears to make the greatest difference in the level of outcome achievement. In addition, ease of accessibility to the center and disabled service delivery staff are significantly related to higher consumer outcomes.

According to multivariate analysis, services received and service characteristics also were the most important factors contributing to consumer outcomes. In particular, housing services, case management, and frequent and personal contact with the center had the most consistent effects on a wide range of outcomes. These analyses found that centers were effective for a broad range of consumers both in increasing and maintaining their independence. Generally, except for VR client status and residence in a supervised setting (both characteristics leading to higher achievement), consumer characteristics did not consistently affect a broad range of outcomes. Finally, while centers with a greater degree of consumer participation in service delivery reported higher outcomes, the data regarding the relationship of disabled directors and consumer-controlled boards to outcomes were inconclusive.

Findings

Consumer achievement as reported by the centers and by consumers themselves is described in detail in Chapter V of this report. Table V-1 in that chapter presents center-reported outcome data, while Tables V-2 through V-6 summarize consumer-reported gains. In addition, Table V-2 distinguishes between those consumers who reported an improved situation (in the five key areas of housing, education, income, or transportation) and those who apparently maintained their situations while in contact with an independent living center.

In order to examine consumer achievement in relation to Standard 3, Table D-3-A (next page) presents the large variety of consumer impacts measured by the study in the context of the Standard 3 outcome areas. As the table indicates, at least 20% of the consumers surveyed reported at least one gain related to each area. One-third or more of the consumers reported improvements in twelve areas: living arrangements (69%), self-direction (66%), personal growth (57%), social skills (49%), communication (46%), personal care (41%), recreation (39%), transportation (38%), housing (38%), assistive devices (37%), education (36%), and income and financial management (36%).

Chapter V and Chapter IX summarize the findings of the multivariate analyses of factors contributing to higher consumer outcomes. They present detail about the effects of services, consumer characteristics, and center characteristics on both center- and consumer-reported out-

Table D-3-A

Consumer Outcomes for Standard 3 Data Elements

Outcome	#	Total N[1]	%
Housing			
Learned about housing options	337	879	38.3%
+Obtained housing modifications	2,244	---	---
Living Arrangements			
Have more independent housing situation	578	841	68.7
Center helped change housing situation	292	875	33.4
+Moved from institution to less restrictive setting	2,030	---	---
Income and Financial Management			
Learned about benefit programs	317	880	36.0
Higher monthly income	296	917	32.3
Learned to manage finances	216	876	24.7
Center helped increase income	97	912	10.6
+Obtained financial benefits	5,542	---	---
Transportation			
+Learned about transportation options	334	877	38.1
Learned to use transportation	298	876	34.0
Transportation situation better	237	915	25.9
Center helped improve transportation situation	224	925	24.2
+Learned to use transportation	5,941	---	---
+Acquired license to drive	264	---	---

Table D-3-A (continued)

Outcome	#	Total N[1]	%
Personal Care			
Learned about personal care assistance	359	878	40.9
Acquired attendants	267	863	30.9
Learned to manage attendants	244	875	27.9
Carried out self-care	226	876	25.8
+Acquired attendants	5,033	---	---
Nutrition			
Learned about health	283	879	32.2
Carried out self-care	226	876	25.8
Household Mangement			
Carry out household/shopping chores	252	875	28.8
Acquired household support	229	874	26.2
+Able to shop/do chores	3,653	---	---
Mobility			
Acquired mobility aids	179	862	20.8
+Acquired mobility, vision, or communication aids	5,472	---	---
Health and Health Care			
Learned about health	283	879	32.2
More healthy and fit	240	879	27.3

Table D-3-A (continued)

Outcome	#	Total N^1	%
Assistive Devices			
Learned about equipment options	326	879	37.1
Learned to use aids	222	874	25.4
Had equipment repaired	153	861	17.8
Acquired adaptive equipment	120	861	13.9
Acquired communication or visual aids	98	863	11.4
+Acquired mobility, vision, or communication aids	5,472	---	---
Education			
Learned about education options	312	879	35.5
Education level changed	221	909	22.3
Learned about affirmative action	193	880	21.9
ILC helped continue education	107	906	11.8
+Achieved educational goals	1,818	---	---
Employment			
Learned about employment options	219	881	24.9
Employmnent situation better	105	892	11.8
ILC helped employment situation improve	78	897	8.7
+Obtained employment	1,548	---	---
Community Involvement			
Belong to more community groups	177	882	20.1
+Gained membership in community organizations	1,170	---	---
+Registered to vote	2,639	---	---

Table D-3-A (continued)

Outcome	#	Total N[1]	%
Recreation			
Learned about recreational activities	340	878	38.7
Participate in more sports	157	880	17.8
Personal Growth			
Feel more self-confident	488	878	55.6
Cope better with disability	454	881	51.5
Feel better about sexuality/ personal relationships	255	881	28.9
Social Skills			
Feel more comfortable in public	427	879	48.6
Feel more comfortable socially	375	879	42.7
Have more friends	325	879	37.0
Communication Skills			
Communicate more assertively	402	879	45.7
Confront infringement of rights	334	875	38.2
Acquired interpreters	40	863	4.6
Acquired readers	32	863	3.7
+Acquired readers or interpreters	5,021	---	---
+Acquired mobility, vision, or communication aids	5,472	---	---

Table D-3-A (continued)

Outcome	#	Total N[1]	%
Self-Direction			
Center helped increase independence:			
-- Rating of 3 or above*	702	762	92.1
-- Rating of "5"*	506	762	66.4
Learned how to acquire necessary services	328	877	37.4
Learned how to use community resources	317	878	36.1
Developed a goal plan	208	877	23.7
Consumer and Legal Rights			
Acquired legal or advocacy services	199	860	23.1

+From Center Mail Survey. All other data from Consumer Mail Survey.

*Scale of 1-5, Very Poor to Very Good.

[1] "Total N" excludes missing cases.

comes. Extensive bivariate analyses were also conducted to help illuminate why some consumers made greater gains than others. The results of this set of analyses are presented in this section.

1. Relationship Between Outcomes and Client Characteristics

When consumer-reported outcomes were analyzed by age, sex, race, age at onset of disability, type of disability, and vocational rehabilitation (VR) client status, only age and VR status were significant factors. In general, younger consumers were more likely to have improvements than older ones. More specifically, those individuals in the 21-40 age group appeared somewhat more likely to achieve life situation improvements (80% reported one or more improvements) than those in the 41-60 category (73%) and much likelier than people 61 or older (57%). While consumers under the age of 21 were also very likely to have made life improvements while in contact with a center, only 54 people in total fell under this category. Similarly, consumers who are now or have formerly been vocational rehabilitation clients appeared more likely to make situation improvements (82% and 79%, respectively) compared to 62% for individuals who have never been VR clients.

These findings are consistent with the fact that older individuals in general are less likely than younger people to experience major life improvements in housing, employment, and education. In addition, this finding confirms field observations that centers generally are not working with older people in institutions to help them achieve greater independence. It also is not surprising that VR client status appears to correlate with consumer achievement. Participation in VR provides access to a range of additional resources that can work in combination with services provided by the center to enhance the consumers' ability to make major life changes. Even those individuals whose cases may have been closed as unsuccessful by the VR system still have benefited from their participation in VR and may be more familiar with the process of setting and working towards goals. VR acceptance may include those consumers who are more capable of achieving life improvements; those VR screened out (based on severity of disability, motivation, infeasibility of improvement, etc.) may indeed have been those less willing or able to make major life gains.

The age and VR status breakdowns for other types of consumer outcomes follow similar patterns. Only achievement in the "aids, benefits, and services" category proved statistically insignificant in relation to age and VR status. The multivariate analyses (see Chapter V) generally confirmed the above findings for age and VR client status.

2. Relationship Between Outcomes and Intensity of Services

One proxy measure of causality, or the extent to which experienced changes are due to center services, is the correlation of services received with outcomes achieved. As might be expected, those consumers in more frequent contact with a center achieved more outcomes (see Table D-3-B). In addition, as Table D-3-B also makes clear, individuals who never go to a center (who receive services by phone or at home) are also less likely to report gains.

Apparently, then, frequency and intensity of contact (assuming that people who visit the center are more deeply involved) do make a difference in consumer levels of achievement. There is also a strong relationship between consumers attributing changes to involvement with the center and whether services were received at the center. Of those consumers who never went to the center, only 32% reported that the center had helped them to achieve major life improvements, contrasted to 57% of those who did visit the center. Finally, another important finding is that working with one staff person who coordinates all services apparently is a significant factor in relation to consumer achievement in only two areas, learning skills and obtaining knowledge.

Multivariate analysis (see Chapter IX) confirmed that frequency of contact and in-person service delivery (either at the center or in the consumer's home) both had consistent effects on a wide range of outcomes. However, case management, which was positively associated with higher outcomes in five of the seven areas, exhibited the most consistent effects of all the service characteristics tested.

Table D-3-C shows that consumers who stated that they worked primarily with disabled staff more frequently reported outcome

Table D-3-B

Consumer Achievement by Frequency and Nature of Contact with Center

	Number of Contacts with Center				Never Go to Center			
	5 or Fewer		6+		Agree		Disagree	
Achievement	#	%	#	%	#	%	#	%
Improvement in Situation**								
One or More	186	66.7%	520	81.0%	180	62.1%	536	82.1%
None	93	33.3	122	19.0	110	37.9	117	17.9
Total	279	100.0%	642	100.0%	290	100.0%	653	100.0
Personal/Social Change**								
One or More	157	56.3%	489	76.2%	146	50.3%	511	78.3%
None	122	43.7	153	23.8	144	49.7	142	21.7
Total	279	100.0%	642	100.0%	290	100.0%	653	100.0
Aids, Benefits, Services**								
One or More	138	49.5%	450	70.1%	168	57.9%	433	66.3%
None	141	50.5	192	29.9	122	42.1	220	33.7
Total	279	100.0%	642	100.0%	290	100.0%	653	100.0
Skills**								
One or More	158	56.6%	507	79.0%	165	56.9%	510	78.1%
None	121	43.4	135	21.0	125	43.1	143	21.9
Total	279	100.0%	642	100.0%	290	100.0%	653	100.0
Knowledge**								
One or More	176	63.1%	542	84.4%	188	64.8%	537	82.2%
None	103	36.9	100	15.6	102	35.2	116	17.8
Total	279	100.0%	642	100.0%	290	100.0%	653	100.0

**Relationship between dependent and independent variables significant at the .01 level except for the relationship between "Aids, Benefits, Services" and "Never Go to ILC," which is significant at the .05 level.

Table D-3-C

Consumer-Reported Outcomes by Disability Direct Service Staff

	Reported Worked Primarily with Disabled Staff			
	Yes		No	
	#	%	#	%
Improvement in Situation*				
One or More	414	78.9%	326	70.1%
None	111	21.1	139	29.9
Total	525	100.0%	465	100.0%
Personal/Social Change**				
One or More	410	78.4%	266	57.0%
None	113	21.6	201	43.0
Total	523	100.0%	467	100.0%
Aids, Benefits, Services**				
One or More	354	67.7%	260	55.7%
None	169	32.3	207	44.3
Total	523	100.0%	467	100.0%
Skills**				
One or More	415	79.3%	278	59.5%
None	108	20.7	189	40.5
Total	523	100.0%	467	100.0%
Knowledge**				
One or More	434	83.0%	309	66.2%
None	89	17.0	158	33.8
Total	523	100.0%	467	100.0%

**Relationship between dependent and independent variables significant at .01 level.

*Relationship between dependent and independent variables significant at .05 level.

achievement in all the areas measured. This conclusion is partially supported by the multivariate analyses (see Chapter IX), which found that working primarily with staff that had a different disability made a difference in the number of achievements reported in three areas.

Bivariate analysis also showed that there is a statistically significant relationship between receipt of nearly all center services and client achievement. Only electronic and communication services were statistically insignificant factors; however, a very small proportion of the consumer sample received these services. These findings were confirmed by multivariate analysis, which also showed which services had the greatest effects on outcomes (see Chapters V and IX).

3. Relationship Between Outcomes and Center Characteristics

Consistent with other findings, consumers at those centers with easier access to the center and its services reported higher levels of achievement. Whether or not situation improvements occurred was related to center proximity to public transportation, center provision of transportation, building accessibility, and ease of phone access to the center. All these accessibility factors also were influential in relation to personal or social changes and acquisition of skills.

Several center characteristics were tested in relation to consumer-reported outcomes. These factors included budget amount, type of area served, size of staff, presence of disabilities among staff and board, type of organization, and years in operation. However, none of these characteristics was statistically significant in relation to consumer achievement within the 36 centers from which the consumer samples were selected. In multivariate analyses, several characteristics had significant and consistent effects on center and consumer-reported individual outcomes (see Chapters V and IX).

Bivariate analyses also indicated a positive and statistically significant relationship between measures of good financial management practices and program outcomes. Centers which had financial mangement systems capable of measuring cost per service were significantly more likely to have consumers reporting higher levels of improvement on four of the five following dimensions, as compared to centers lacking such management capability: situational improvements; receipt of aids, benefits and services; gains in skills; gains in knowledge; and gains in personal, psychological and community situation. In addition, centers with the capability of determining costs per service and of calculating cost per consumer were more likely to have trained a much higher number of other professionals in the community in dealing with the needs of disabled individuals.

No statistically significant relationships were found between evaluation practices and program outcomes in bivariate analyses. However, centers issuing evaluation reports also were more likely to train higher numbers of community professionals in the special needs of persons with disabilities.

Multivariate analyses (see Chapter IX, Table IX-3) revealed that determining average cost per service and documenting consumer goal achievement did make a difference in a few outcome areas. Consumers from centers claiming they follow these practices reported more gains in some areas. However, centers using the financial procedures reported fewer consumers that acquired attendants. For the most part, evaluation practices and financial management capability did not have a consistent and significant effect on a broad range of program outcomes.

4. Relationship Between Outcomes and Major Purpose for Using Center Services

As described in Chapter V, consumers had different primary purposes in using center services. One group of consumers clearly sought to increase independence, while others wished to maintain current levels of independence, to obtain information, or had some other purpose.

Analysis of consumer achievement in terms of major purpose shows that individuals seeking to make gains in independence are generally more likely to report outcomes. A higher proportion of "gain" consumers recorded personal or social changes, skill acquisition, and increased knowledge. However, major purpose in seeking center services was not statistically significant in relation to improved situations or to aids, benefits, and services. Apparently, while those consumers with higher expectations for center services and more ambitious goals were able to achieve some changes in their lives more consistently than other consumers, they were not necessarily more likely to benefit from major life improvements. The effects of major purpose on outcome achievement were also mixed in the multivariate analysis (see Chapter IX).

STANDARD 4: COMMUNITY OPTIONS

The Center shall increase the availability and improve the quality of community options for Independent Living, in such areas as, but not limited to, the following:

4.1 Housing
4.2 Transportation
4.3 Personal care
4.4 Education
4.5 Employment
4.6 Communication
4.7 Reduction of barriers, including architectural and social
4.8 Disability awareness and social acceptance
4.9 Recreation
4.10 Consumer involvement in civic activities and community affairs
4.11 Physical and mental health care
4.12 Legal services

A. Description and Purpose of Standard

The purpose of this standard is to improve a community's social and physical environment for persons with severe disabilities. Standard 4 requires centers to develop options that enable disabled individuals to live independently. Without appropriate community options, these individuals are restricted to dependency upon families or nursing homes. If persons with disabilities are to live like other citizens, they need accessible and affordable housing, transportation, personal care, and other environmental improvements.

B. Summary of Achievement

Overall, centers reported 27,145 community impacts across the various outcome areas. On average, 66% of the centers could report outcomes in community development areas applicable to their programs. Not surprisingly, centers which specifically gave priority to some kinds of community development areas were more likely to achieve impacts in those areas. There was a statistically significant relationship between impacts and such goals as barrier reduction, recreation, personal care, and communication. In addition, bivariate analysis showed that centers with the following characteristics reported higher levels of impact in at least some areas: a non-rural setting; a disabled director; at least half the staff with disabilities; a wide range of disabilities served; a greater community development focus; a stronger independent living philosophy. Multivariate analyses showed that free-standing status, a larger budget, experience, a smaller service area, philosophy, and financial and planning management capabilities were all related to higher center achievement when controlling for the effects of other factors.

Among other community agencies surveyed in the centers' locales, there was greatest agreement that independent living centers had substantial impacts in the areas of personal care (63%), disability awareness (59%), and transportation (45%). Housing, consumer involvement and barrier removal were also areas that a large proportion of other agencies believed centers had affected in their communities.

C. Findings

Table D-4 summarizes center-reported achievement for most of the community option areas listed in Standard 4. As discussed in Chapter VII, the highest outcome levels were reported in the two "training" categories: other service providers and health providers trained in the special needs of persons with disabilities represented 23% and 19%, respectively, of the total number of outcomes reported. Adding qualified attendants to the community pool (12%) was the third highest outcome area reported. Please see Chapter VII for discussion of the problems centers experienced in reporting community impacts. Table VII-6, in particular, provides detail about how many centers recorded achievement in areas targeted by their community development efforts.

Two Standard 4 data elements not covered in Table D-4 are 4.8, Disability Awareness and Social Acceptance, and 4.12, Legal Services. While 87% of the centers reported that they target promotion of disability awareness in their programs, to assess the effectiveness of center efforts it would be necessary to measure changes in general public attitudes. However, nearly 60% of the community agencies surveyed felt centers had substantially affected disability awareness in their community, indicating that the local social service community believes centers are performing well in this area. In contrast, only

Table D-4

Center-Reported Community Impacts for Standard 4 Data Elements

Community Impact Area	Average #($) of Impacts per Center	Range	Total #($) of Impacts
Housing			
Accessible Housing Units	22	1-150	1,806
Transportation			
Accessible Vehicles Added to Public Transportation System	29	1-350	979
Personal Care			
Attendants Added to Community Attendant Pool	45	2-201	3,227
Additional Funding Raised for Attendants, Readers and/or Interpreters	\$11,588[1]	\$100-\$1,000,000	\$7,486,669
Education			
Agreements Established with Special Education/Other Agencies	10	1-90	846
Educational Resources Made Accessible	7	1-100	352
Employment			
Jobs Developed	17	1-112	1,024
Communication			
Communication Devices Made Available	10	1-100	588
Readers Added to Community Pool	8	1-50	335
Interpreters Added to Community Pool	6	1-34	280
Reduction of Barriers			
Ramps or Curb Cuts	32	1-200	2,302
Accessible Public Buildings	12	1-100	958
Brailled Information	14	1-150	541
Brailled Elevators	6	1-100	296
Parking Spaces	23	1-250	1,462
Recreation			
Recreation Programs Made Available	12	1-250	976
Consumer Involvement in Civic/ Community Affairs			
Consumer Memberships in Community Groups	14	1-252	1,170
Disability Awareness			
Health Providers Trained	18[1]	1-651	5,067
Other Service Providers Trained	19[1]	1-501	6,106

[1] Median reported rather than mean.

14% of the centers reported targeting legal services, confirming site visit observations that most centers refer individuals to other agencies for this service. Community agencies concurred with this finding that legal services are a low priority, with only 10% reporting that centers have substantially affected the availability of these services.

Statistical analysis shows that centers which specifically gave priority to some kinds of community development goals were more likely to achieve higher levels of impact in those areas. Centers targeting personal care reported adding an average 49 attendants to the community pool, compared to an average 17 for those centers without a personal care focus in their community development programs; these same centers claimed they helped raise an average $173,000 in additional personal care attendant funding compared to an average $4,000 for the remaining centers (these findings are both statistically significant at the .05 level). Similarly, centers targeting barrier reduction claimed credit for an average 13 buildings made accessible compared to four (significant at the .01 level); centers targeting recreation helped establish an average 18 programs compared to four for the other centers (significant at the .05 level); and centers targeting communication reported adding an average 14 communication devices compared to an average six for the remaining centers (significant at the .2 level). All of these findings hold even when controlling for the effects of center size on the number of impacts reported.

Additional bivariate as well as multivariate analyses were undertaken to determine which organizational characteristics were significantly associated with center success in developing community options. For the results of these analyses, please see Chapter VII.

STANDARD 5: SERVICES

The center shall provide to disabled individuals within the center's target population and/or their families the following Independent Living Services:

5.1 Advocacy
5.2 Independent living skills training (e.g., health care, financial management, etc.)
5.3 Peer counseling

In addition to the services above, the Center may provide or make available other services such as, but not limited to, the following:

5.4 Legal services
5.5 Other counseling services (e.g., non-peer, group, family)
5.6 Housing services
5.7 Equipment services
5.8 Transportation services
5.9 Social and recreational services
5.10 Educational services
5.11 Vocational services, including supported employment
5.12 Reader, interpreter, and other communication services
5.13 Attendant and homemaker services
5.14 Electronic services

A. Description and Purpose of Standard

The intent of this standard is to ensure that independent living center services are responsive to the needs of persons with disabilities and their families, and that services are designed and organized to achieve the primary objective of assisting persons with disabilities to live as independently as possible. Although this standard is not intended to affect the diversity that exists in center service configurations, it does indicate that centers are expected to offer the types of assistance that appropriately support the independent living goals of persons with disabilities and their families. Under this standard, three services have been designated as "core" services to be provided by all centers: advocacy independent living skills training, and peer counseling, all of which have been identified as essential support mechanisms for persons seeking to live independently. In addition, centers may offer a range of other types of services that match the particular needs of their service locale.

B. Summary of Achievement

Independent living centers appeared to be highly responsive to the requirements of the service standard. The majority of centers provided the core services of advocacy, independent living skills training, and peer counseling. Moreover, there has been extensive provision of services related to such areas as housing, equipment, transportation, personal care assistance, and social/recreation.

Substantive variations in how core services have been organized and delivered reflect the organizational, historical, and geographic differences that characterize the centers themselves. Current variations do not necessarily diminish the integrity of the service model, but suggest that each service has a range of possible delivery options.

While the majority of IL Centers offered the key services, in some cases the frequency of provision was significantly influenced by certain factors. Rural centers, for example, tended to provide a narrower range of services than other centers. Centers with a larger percentage of staff with disabilities were more likely to provide peer counseling. Also, centers with larger numbers of consumers more frequently provided attendant/homemaker services.

C. Findings

The types of services provided by the centers are fully described in Chapter IV. However, Table D-5 provides additional detail about the relationships between center characteristics and whether or not a service is offered. These findings can be summarized as follows:

- Advocacy services were generally equally likely to be provided by all types of centers regardless of center characteristics such as funding level, type of organization, or degree of consumer participation, although they were more likely to be offered by centers that had been in operation longer.

- Independent living skills training was provided by all types of centers. In general, centers surveyed were equally likely to provide these training services

Table D-5

Relationship Between Center Characteristics and Services Offered[a]

	Center Characteristics										
Services Offered	Free Standing Agency	Total Agency Budget	Years in Operation	Part B as % of Budget	Community Development as % of Effort	Rural Service Area	Disabled Director	Disabled Staff	Direct Grantee	Partial State Service Area	Disabled Board
Advocacy			-*	-		-	+		-	+	
ILS Training	-	+				-	-		+		
Peer Counseling	+*						+*	+**	+		+*
Legal				-	-	-					
Professional Counseling				-	-		+			-**	+
Other Counseling	-**		-		-	-					
Housing		+*	-	-*	-	-**	+		-	+	
Equipment	-	+	-	-	-			+			-
Transportation		+		-	-*	-*	+		-		+
Recreation	-*		-	+	-	-					
Educational	-*	+	+*	-							-
Vocational	-	+		-		-					
Communication	-								+*		
Attendant		+	-	-	+	-*	+	+		+	
Electronic	-	+				+*		-	+	-**	
Family Support						-			-	-	+
I and R		+*		-*			+	+*	+*	-	+*
Other			-	+		+			+		

[a] based on Pearson Correlation Coefficients

KEY

+ or - = relationship significant at .2 level

* = relationship significant at .05 level

** = relationship significant at .01 level regardless of their individual center characteristics. (None of the correlations were significant at the .05 level).

- Most centers provided peer counseling services regardless of their geographical service area, funding levels, or caseload size. However, there were other variations in the types of centers offering peer counseling. Centers with more disabled staff were more likely to provide the service (92%) than those with fewer disabled staff (73%). Centers with a majority of disabled board members were also more likely to provide peer counseling (92%) than those whose boards had fewer disabled members (78%). Free-standing centers were more likely to provide peer counseling (90%) than those operating within umbrella organizations and centers with disabled directors were more likely to provide peer counseling (92%) than those with non-disabled directors (81%).

- All centers surveyed were equally likely to provide legal and paralegal services.

- Centers with a larger total agency budget were more likely to offer housing (87%) than smaller budget centers (49%). Fewer rural centers (57%) offered housing than those serving urban and suburban areas (89%). Centers that have been in operation longer were more likely to offer housing services, and those whose total budget was composed of a higher percentage of Part B funds, were less likely to provide these services than centers with less Part B funding.

- Centers were equally likely to provide equipment services regardless of their characteristics.

- Centers less likely to provide transportation were those with a higher percentage of their budget used for community development activities and, not surprisingly, those in rural areas.

- Free-standing centers were less likely (32%) than those operating with umbrella organization (48%) to provide social and recreational services.

- The longer a center had been in operation, the more likely it was to provide educational services.

- All types of centers were equally likely to offer family support services.

- All centers were equally likely to provide vocational services, with one exception. For those centers operating within an umbrella agency, the types of umbrella agency was related to the provision of vocational services. Centers with non-profit umbrella agencies were more likely to provide vocational services than centers operated by VR, presumably because vocational services were already being offered by the umbrella agency.

- Centers that subcontract with state vocational rehabilitation agencies were more likely to provide cummunication services than VR agencies or direct center grantees.

- Centers serving a rural area were less likely than those serving an urban area to provide attendant/personal assistance services.

STANDARD 6: INFORMATION AND REFERRAL

The center shall provide Information and Referral to all inquirers including those from outside the center's target population.

A. Description and Purpose of Standard

The rationale underlying this standard reflects the importance of access to information and referral services for persons with disabilities. In addition to the varied types of direct assistance provided by IL Centers, persons with disabilities need information related to the issues, options and resources that influence their ability to achieve an independent lifestyle.

Referral assistance is also essential since achieving independence often requires the involvement of a variety of agencies and community organizations. Under this standard, independent living centers are required to provide the information and referral assistance to any individual seeking to achieve or to learn about resources for independent living.

B. Summary of Achievement

The Part B program has been characterized by extensive provision of information and referral services. Regardless of level of funding, oganizational structure, or location, most centers have provided this service. Over 80% of the sample provided I & R services and over 60% of the consumer sample reported receiving I & R assistance. Comparisons across different types showed that although the majority of all types of centers provided I & R services, not all types of centers were equally likely to provide I & R. Centers with a majority of disabled board members were more likely to provide I & R services (89%) than those with fewer disabled board members (78%). Similarly, centers with a majority of disabled staff were more likely to provide I & R (90%) than those with fewer disabled staff (79%). Also, centers which were direct grantees were more likely to provide I & R (96%) than those subcontracting with VR (81%).

Centers also established referral relationships with a wide variety of agencies which included vocational rehabilitation, primary care and rehabilitation agencies, housing and transportation agencies, mental health and mental retardation agencies, and disability related organizations. Centers vary in how they organize and deliver I & R services, with the major variation reflecting the extent to which I & R is fully staffed and supported by the development of a resource library or directory. Some Centers have a fully developed I & R system with staff specialists and centralized resource materials. Most centers provide I & R through a more informal mode in which all service staff assume responsibility for responding to I & R calls. In both cases, I & R serves additionally as an intake mechanism for consumers seeking assistance.

C. Types of Referral Relationships Developed by Independent Living Centers

In order to identify consumers in need of services and to provide appropriate referral assistance, centers have developed a network of contacts and referral relationships with other agencies. Referral services have also required that centers develop an information base about the various types of agency services that are available to consumers in their service locale as well as an awareness of how consumers can access such services. The study examined the extent to which centers received referrals from certain types of agencies as well as the extent to which they made referrals to various agencies.

The community agency mail survey responses indicated that centers have established referral relationships with a wide variety of agencies -- 75% of the respondents indicated that their agencies refer consumers to centers, and 56% indicated that their agencies receive referrals from centers. The findings from the center mail survey indicated that the major sources from which over 60% of the centers received referrals were the state vocational rehabilitation agency, primary care facilities, mental health/mental retardation agencies, medical service providers, rehabilitation facilities, disability related organizations, and welfare or social service agencies. Centers most frequently referred consumers to such agencies as the state vocational rehabilitation agency, welfare or social service agencies, housing agencies, the social security office, mental health/mental retardation agencies, transportation agencies, disability related organizations, and Medicaid. The extent of referral relationships reported by the centers is depicted in Table D-6.

There was some variation in referral relationships across different types of centers. Those with a higher representation of individuals with disabilities on their boards were more likely to refer consumers to state vocational rehabilitation agencies. Those centers with a higher percentage of disabled staff were more likely to refer consumers to other independent living centers. The larger the center, the more likely it was to refer consumers to state vocational rehabilitation agencies and medical providers.

Table D-6

Independent Living Center Referral Relationships

Agency Type	% ILCs Receive Referrals	% ILCs Make Referrals
State Vocational Rehabilition Agency	88.4%	86.8%
Primary Care Facility (hospital, nursing home)	85.1	44.6
Mental Retardation/Mental Health Agency	76.0	77.7
Rehabilitation Facility	70.2	66.1
Doctor or Medical Care Provider	68.6	53.7
Disability-Related Organization	67.8	78.5
Welfare or Social Service AGency	67.8	86.8
Special Education Agency/Program	66.1	37.2
Agency for Aging	61.2	66.1
Advocacy Group	51.2	62.9
Private Vendors or Services	48.8	64.5
Housing Agency	47.9	86.0
Other Independent Living Centers	46.3	62.0
Employment Agency	38.8	67.8
Other Educational Organization	35.5	39.7
Social Security Office	33.1	85.1
Legal Service Organization	33.1	76.0
Medicaid Agency	30.6	71.9
Transportation Agency	22.3	79.3
Business/Corporations	14.9	32.2
Lobbying Groups	9.9	18.2
Other	91	7.4

STANDARD 7: COMMUNITY ACTIVITIES

The center shall conduct activities to increase community capacity to meet the needs of individuals with disabilities, such as, but not limited to, the following:

7.1 Advocacy and technical assistance services to improve community options, remove community barriers, and create access to public programs
7.2 Public information and education (e.g., presentations, press)
7.3 Outreach to consumers and service providers
7.4 Initiatives to establish an active role in the disabled community

A. Description and Purpose of Standard

Standard 7 calls on centers to develop activities and services to expand community options for persons with disabilities. Community activities may include advocacy, technical assistance, and public information. Another method for expanding community opportunities is outreach to service agencies and other local organizations. As a result, more consumers can be referred to centers or participate in various activities and services. Finally, under Standard 7, centers are expected to be active leaders in organizations of persons with disabilities or, if such organizations do not exist, help foster and provide leadership for a disabled community.

B. Summary of Achievement

On the average, independent living centers devoted 25% of their efforts to community-oriented activities. Nearly one-third (31%) allocated over 30% of their resources to catalytic activities in the community.

Of the community agencies surveyed, 74% rated their local centers as highly effective advocates for persons with disabilities ("4" or "5" on a five-point scale), and nearly 56% reported that contact with a center led to an increase in their own efforts to create options for disabled persons. While the highest number of agencies (75%) report they refer consumers to a center, the second most frequently reported relationship (60%) is the receipt by the agency of technical assistance and information from the center. Centers' most frequently reported relationships were also coordination of service delivery with other providers and provision of information and technical assistance.

While it is difficult to assess the results of center outreach efforts, consumer survey results show that 62% of the consumers learned about centers from community agencies, indicating that other organizations had been informed about centers and that they have some degree of confidence in them. Moreover, the overall distribution of center consumers by disability approximates the national distribution of disabilities among the population (see Standard 1).

C. Findings

Although centers report spending a significant amount of time in community activities (25% on the average), site visit discussions suggest that even this figure may tend to underestimate center efforts devoted to community development activities. In smaller centers that do not have specific staff designated to community development activities, staff sometimes found it difficult to estimate the level of community-oriented activity. Also, because some centers are reportedly discouraged by their funding sources from allocating resources to community activities that are considered to be more appropriately spent on direct consumer services, these centers may not have a good system for documenting activities that are not client-oriented. In addition, some staff reported that they spend a great deal of their personal time representing the center in community activities -- on boards, commissions and task forces -- that they did not report in their estimates.

Results concerning data elements 7.1 through 7.4 of this standard are described in Chapter VII of this report, which covers centers' advocacy and technical assistance efforts, public information activities, outreach, and their leadership roles in the disabled communities. Chapter VII also details the types and frequency of center relationships with a wide range of other local agencies.

Achievement of Standard 7.4, center initiatives to establish an active role in the disabled community, is difficult to measure. As reported in Chapter VII, site visits provided several examples of how centers created and maintained a sense of community among disabled individuals. However, there are some other indicators -- based on survey data -- of center impacts in this area. First, 20% of the consumers surveyed reported that they belonged to more community groups as a result of their contact with an independent living center. Centers reported that nearly 1,200 of their consumers gained memberships in community governing boards, committees, and councils. They also reported that more than 2,600 consumers registered to vote. These results indicate that centers are involving more disabled people in community activities.

STANDARD 8: CONSUMER INVOLVEMENT

Qualified disabled individuals shall be substantially involved in the policy direction, decision-making, service delivery, and management of the Center, and given preference as:

8.1 Members of Boards of Directors (at least 51% qualified disabled persons)
8.2 Managers and supervisors
8.3 Staff

A. Description and Purpose of Standard

Standard 8 proposes that substantial consumer participation in key management, service delivery and policy-related roles comprises an integral part of center practice. Historically, service systems involved with persons with severe disabilities have been based on the assumption that professionals can better identify the appropriate service needs of patients or consumers. Thus, individuals with severe disabilities have often been excluded from participating in the definition of their own services. Standard 8 was developed with the intention of providing guidelines for consumer involvement in the articulation and actualization of independent living programming. It presents the further possibility of centers providing career opportunities and employment training for individuals with severe disabilities. Finally, the active involvement of qualified persons with disabilities in center decision-making roles results in consumer exposure to a range of peer role models, a dynamic considered important in promoting independent living.

B. Summary of Achievement

Study findings indicate that there was considerable participation of persons with disabilities in key management, decision-making, and other staff and volunteer roles. On a five-point scale, centers rated the importance of consumer involvement at levels of (a) 4.0 in relation to controlling the policy direction and management of centers, (b) 4.2 in establishing service priorities, (c) 3.7 in managing center operations, and (d) 4.3 in participation in important staff roles. Community agencies surveyed confirmed center commitment by rating these same aspects as major emphases in local centers at an average 3.9 level.

Consumers indicated, with a mean response of 4.3, that persons with disabilities were involved in key center staff and management positions. Thirty-two percent of consumers had assisted in center operations through paid or volunteer positions.

Across all centers, persons with disabilities comprised:

- more than half (52%) of the total members of boards of directors;
- 72% of advisory board members;
- 62% of center directors;
- 51% of total staff (including administration, direct service, support, and other staff); and
- a majority (58%) of volunteers.

It should be noted, however, that at one extreme of the respondents surveyed, centers existed with few or no consumer representatives. Recruiting and training persons with disabilities who are highly qualified or have potential for skill development to fill key decision-making and staff positions remains a critical issue for centers.

C. Findings

Table D-8 describes the relationship between eight center characteristics that are not specifically related to consumer involvement and four characteristics which are specifically related. Of particular note are the following:

- a significant (at 0.1 level) percent (80.6%) of free-standing centers report a majority of boards of directors members with disabilities;
- 63.4% of free-standing centers reveal an average score of 4.4 or better (on a 1 to 5 scale) on independent living philosophy emphasis (at a .05 significance level);
- more than half (57.0%) of centers that are not direct grantees of Part B funding have a director with a disability as opposed to 32.0% of direct grantee centers (significant at .05 level);
- as annual budgets increase, the percentage of centers

Table D-8

Relationship Between Consumer Participation in Center Operations and Other Center Characteristics

	Disabled Director	Disabled Majority on Board	Disabled Majority on Staff	IL Philosophy Score 4.4+ (on Scale of 1-5)
Organizational Status		**		**
Free-standing	54.9%	80.6%	54.9%	63.4%
Within Umbrella	47.9	16.7	41.7	31.9
Direct Grantee	*			
Yes	32.0	60.0	44.0	36.0
No	57.0	54.3	51.6	55.4
Total Annual Budget		**		*
Less than $175,000	48.6	22.9	40.0	31.4
$175,000 to $300,000	50.0	55.3	55.3	54.1
More than $300,000	51.4	76.3	42.1	57.9
Part B as % of Budget		*		*
Less than 33%	60.0	67.7	35.5	64.5
33% - 66%	45.2	58.1	54.8	51.6
More than 66%	45.8	37.5	45.8	34.0
Years in Operation	**			
Less than 4 Years	34.3	51.4	51.4	39.4
Five Years	66.7	49.0	56.0	58.8
Six or More Years	47.1	65.7	37.1	48.6
Rural-Only Service Area				
Yes	48.3	44.8	58.6	46.4
No	52.7	57.6	46.2	51.6
State Service Area				
Serves All of State	41.7	62.5	41.7	50.0
Serves Part of State	54.2	52.6	51.0	50.5
Community Development as % of Effort			*	
19% or Less	44.4	40.5	29.7	38.9
20% -30%	58.5	51.2	60.0	51.2
31% or More	52.8	66.7	52.8	63.9

*Relationship significant at .05 level
**Relationship significant at .01 level

with a majority of persons with disabilities on boards of directors and scores on center emphasis on independent living philosophy increase (at .01 and 05 significance levels, respectively);

- centers with less than 33% Part B funds as part of budgets show a majority of board members with disabilities and 64.5% report a 4.4+ independent living philosophy score, while lower percentages are shown for centers with 33-66% Part B, and even lower ones for centers with more than 66% in both categories (all at .05 level);
- a majority of centers (66.7%) that have been in operation for five years report directors with disabilities while less than half (34.3%) of "younger" and "older" (47.1%) centers have disabled management (at .01 level);
- when centers indicate 20-30% as level of community development effort, 60% operate with a majority of staff with disabilities. As efforts increase to 31% or more, 51.2% of centers have a majority of staff with disabilities. As effort level decreases to 19% or less, only 29.7% of centers report a majority of staff with disabilities (all at .05 level).

Other findings related to consumer involvement in centers have been noted in Chapter VI of the main report, entitled Consumer Participation. It is apparent from these findings that consumer involvement remains a critical and sometimes controversial issue as centers grapple with the dynamics of developing disability representation while ensuring that staff are fully qualified to provide and manage quality programs.

STANDARD 9: PROGRAM AND FINANCIAL PLANNING

The center shall establish clear priorities through annual and three-year program and financial planning objectives which include, but are not limited to, the following:

9.1 Overall center goals or mission
9.2 Work plan for achieving goals
9.3 Specific objectives for numbers and disabilities of individuals to be served
9.4 Service priorities and needs to be addressed
9.5 Types of services to be provided and service deliver procedures
9.6 Annual, three-year, and alternative budget projections

A. Description and Purpose of Standard

This standard is intended to promote sound organizational procedures. Its purpose is to create a clear expectation that centers will engage in annual and three-year planning activities that will contribute to the establishment of priorities and internal standards of accountability. Under this standard, centers are expected to have a written mission or goal statement, and are expected to develop specific work plans, service priorities and objectives, overall center service plans, and financial projections.

B. Summary of Achievement

The center mail survey requested information on nine program and financial planning procedures (see Table D-9). Survey results indicate that generally centers followed the procedures relevant to the objectives of this standard. Almost half of respondent centers used all or all but one of the planning procedures included in the survey, and almost three-fourths used six or more.

Most centers (82%) engaged in formal annual planning procedures. Site visit interviews revealed that center Boards of Directors generally participated in this process, in some cases taking the lead and in others following staff recommendations. Formal planning was often conducted in the context of applying for grants.

Nearly all centers (97%) also reported the development of written mission or goal statements that reflect independent living philosophy. Based on site visit findings, it appears that most Board members,

Table D-9

Percentage of Centers Reporting Use of Nine Program and Financial Planning Procedures

Procedure	% of Centers
Annual budget projection	98%
Written independent living mission or goal statement	97
Written description of types of services to be provided and service delivery procedures	94
Annual priorities and needs to be addressed	92
Annual planning procedures	82
Written work plans for achieving goals	73
Specific objectives for numbers and disabilities of individuals to be served annually	59
Long-term budget projection	35
Three-year plan for services and consumers to be served	27

administrators, and staff understood the independent living philosophy and its relationship to their center's overall goal.

About 73% of the centers prepared written work plans with timelines for achieving objectives. These plans frequently were developed as part of grant applications for funds to provide new services. As researchers observed in the field, the quality of these work plans varied considerably. Some centers developed tasks, staff assignments, and timelines in great detail, while others prepared rather perfunctory plans.

Some centers reported during site visits that they consider defining specific objectives for numbers and disabilities of individuals to be served to be inappropriate for their programs, since their intent was to simply meet the demand in the local community. Thus, it is perhaps not surprising that fewer centers (59%) reported using this procedure. Many of the centers indicated during site visits that specific objectives typically were created only to meet grant requirements, and are not widely used as a planning tool. In addition, very few of the centers (27%) developed three-year plans for services and consumers to be served.

However, nearly all the respondent centers (92%) prepared annual service priorities and identified needs to be addressed. These priorities often reflected the background of center personnel, the needs of the broad population with disabilities, and gaps in service provision by other providers.

Nearly all centers (94%) also could provide written descriptions of their services and service delivery procedures. These descriptions frequently were in the form of brochures identifying each service and containing a brief description of the center's service delivery philosophy. Some centers developed elaborate procedures manuals based on VR procedures, though in general manuals were not commonly found. In addition, most centers (88%) reported that they had written policies and procedures for Board and staff, which specified the roles and responsibilities of each.

Annual budget projections were prepared by nearly all centers (98%); however, many fewer (35%) conduct long-term budget projections.

Administrators reported during site visits that funding opportunities change so frequently that long-term projections often are not useful. Instead, centers must look for funding opportunities and take advantage of them whenever possible.

C. Findings

Little variability existed among centers in program and financial planning, in that a high proportion of centers reported using most planning procedures. For those specific procedures which centers generally did not follow (setting objectives for consumers to be served, developing three-year plans for services provided and consumers served, or projecting long-term budgets), an attempt was made to determine if there were significant differences between centers which used the planning procedures and those that did not. Of several center characteristics tested, only the length of time in operation proved to have a significant relationship with whether a center developed three-year plans or projected long-term budgets. Centers in operation for four years or longer tended to conduct longer-term program and financial planning. The percentage of disabled on a center's staff or Board, percentage of annual budget represented by Part B funding, service area, non-profit status, or organizational status (free-standing versus within umbrella) were not related to the three procedures discussed above.

Centers, for the most part, complied with the objectives of Standard 9 by following specific procedures important for program and financial planning. However, it appears that generally only older centers engaged in longer-term planning for services and for financial health. In addition, while there was relative uniformity in the extent to which centers do plan, field research revealed that the quality of that planning varied considerably.

STANDARD 10: ORGANIZATIONAL AND PERSONNEL MANAGEMENT

The center shall use sound organizational and personnel management practices.

10.1 Written policies and procedures for Board and staff which specify appropriate roles and responsibilities

10.2 Job descriptions for all personnel, including volunteers

10.3 Clear lines of authority and supervision

10.4 Personnel performance appraisal and guidance

10.5 Equal opportunity and affirmative action policies and procedures

10.6 Staff and Board training and development

A. Description and Purpose of Standard

The organizational principles which comprise Standard 10 provide the foundation for the successful management and structuring of the centers. Research in organizational management has highlighted the importance of these basic principles which enhance communication between administration, boards and staff, delineate lines of authority, protect personnel rights, and encourage ongoing education and training of involved personnel. Such dimensions of organizational practices are critical to creating an environment for successful service provision, and thus, overall center accomplishments. Standard 10 attempts to illustrate the basic components necessary for running the centers in an equitable, responsible, and well-organized manner.

B. Summary of Achievement

As Table D-10 shows, center survey response indicated that the number of standard personnel management practices present overall was quite high. Eighty-seven percent of respondent centers followed six or more of the eight procedures included in Table D-10. The least prevalent practice was center-supported training and development of boards of directors and staff (73%), which perhaps reflects that a large number of centers at a fairly early stage of organizational development. Responses ranges from 88% to 100% on use of all other personnel management procedures, indicating that centers are developing and maturing into well-run organizations.

Table D-10

Percentage of Centers Reporting Use of Eight Standard Personnel Management Procedures

Procedures	Percentages
Written personnel policies and procedures	100%
Written job descriptions for all personnel	100%
Organizational chart showing job responsibilities, authority, and supervision	98%
Center-supported staff training and development	95%
Written affirmative action and equal opportunity policies and procedures	93%
Written personnel performance evaluations at least once a year for all staff	93%
Written policies and procedures for Board and staff specifying roles and responsibilities.	88%
Center-supported Board training and development	73%

C. Findings

A comparison was made between centers which have incorporated board and staff training into management practice and those which have not. A crosstabulation reveals that board and staff training is significantly more likely to be found in centers which:

- have a majority of Board members who are disabled (85% versus 59% of centers without a majority of disabled Board members);
- are larger in size and have larger budgets (89% versus 65% of centers with smaller budgets); and
- are free-standing agencies (84%) rather than a part of an umbrella organization (59%).

Observations from site visits substantiate the survey findings on center management practices. While many centers are still growing and developing personnel practices, most centers had written documentation of many of the practices available for perusal, as well as evidence of implementation on a day-to-day basis.

Personnel practices of centers within an umbrella, especially those that were part of state government, tended to be more formalized and highly developed, and at times were more rigid. In some cases, the more formal management practices acted to limit the number of staff with disabilities a center could recruit and hire, while in other cases the added structure worked to a center's benefit. One center reports that its management and functioning improved after it hired a new director who had previously worked in the state government and brought more structure to the center.

Policy and procedures manuals were found in almost all of the centers (88%), primarily related to staff rather than Boards of Directors. All centers had written job descriptions which varied in detail by center and according to the position described. These can often become dated in growing centers, requiring frequent revisions and additions. One center included consumer civil rights advocacy in every job description.

Ninety-four percent of the centers had written EOP and affirmative action policies and procedures. One center had a policy of always interviewing any person with a disability and promoted persons with disabilities from within. Many centers clearly preferred to employ persons with disabilities, but did not have active recruitment or advancement mechanisms. Again, a tension existed in adherance to affirmative action practices as centers struggled to find a balance between level of qualifications and a preference toward hiring persons with disabilities who may not have the extensive employment background of non-disabled peers competing for the same position.

Although 93% of the centers incorporated yearly written staff evaluations into management practices, service demands and center growth affected the systematic implementation of this practice. Centers which were part of umbrella agencies tended to have well-developed systems for staff appraisals, while developing centers generally provided feedback on a more informal, ongoing basis.

The Centers for Independent Living Program as a whole appeared to be incorporating sound organizational and personnel practices into daily operations. These practices were often in a process of refinement and development, as centers continued to expand services to meet the needs of persons with disabilities. Board and staff training and development seemed to be the weakest area for most centers, especially among those who did not have a majority of Board members with disabilities. Finally, site observations suggested that centers that functioned as part of an umbrella organization in some cases had less flexibility in organizing and managing personnel, while in other cases the presence of umbrella agency structure served to resolve many problems.

STANDARD 11: FISCAL MANAGEMENT

The center shall practice sound fiscal management.

11.1 Annual budget that identifies funding sources, and the allocation of resources across services and activities

11.2 Budget monitoring system and procedures for managing cash flow

11.3 Annual audit by independent public accountant

11.4 Resource development activities (e.g., grant development, securing fee-for-service agreements, business development) appropriate to achievement of objectives

11.5 Determination of costs of services and activities (total program cost, cost by funding source, service component costs, average cost per service and per individual served)

A. Description and Purpose of Standard

This standard probes whether centers have in place conventional practices and financial information systems which foster sound fiscal handling of funds received, adequate planning, and accountability to those governments and taxpayers which have provided the funds. Such practices should facilitate making financial reports and passing audits without difficulty. They should help the centers avoid problems in serving consumers in a timely fashion due to cash flow, and should make evaluation and planning more useful by permitting centers to understand the actual unit costs ot services being proposed for delivery, and the costs of achieving different consumer impacts.

B. Summary of Achievement

As Table D-11 illustrates, almost all centers used fiscal management practices required by the first four data elements of Standard 11. The average number of procedures which centers had in place is nine, and only 35% used all or all but one of the 13 practices shown in Table D-11. Many centers needed improvement in determining costs of services and activities.

Virtually all centers (96%) reported having annual budgets that identified funding sources and the allocation of resources across services and activities. Indeed, 92% of the centers were consistently able to provide data the survey requested on total funding and the sources of that funding. The 8% of centers that lack even such basic financial

Table D-11

Percentage of Centers Reporting Use of 13 Fiscal Management Procedures

Procedure	%
Budget monitoring system	97%
Total program cost	97
Annual budget that identifies funding sources and resource allocation	96
Grant development	96
Costs by funding source	95
Procedures for monitoring cash flow	92
Annual audit by independent public accountant	86
Fee-for-service agreements	73
Costs by service component	63
Computerized fiscal systems	60
Average cost per service	49
Average cost per individual served	49
Business development	43

data should remain a policy concern, however. Almost all centers (97%) reported having a budget monitoring system in place, and 92% reported having procedures for managing their cash flow. Most (86%) centers reported having annual audits conducted by an independent public accountant.

Centers varied in their participation in different resource development activities. Almost all centers engaged in grant development (96%). Interviews during the site visits revealed that because of the uncertainty of their funding bases from one year to the next, some centers were putting a disproportionate amount of effort into fund-raising. In some of these centers, direct services may have suffered as a result.

The large majority (73%) had established fee-for-service agreements, including the development of copayment schedules or contracts with other agencies (VR, nursing homes, health agencies, etc.). However, not all these centers had the necessary information on the costs of their services to implement such systems effectively.

A surprisingly large minority (37%) were engaged in business development. At last one center is seriously beginning to explore the revenue generation possibilities of for-profit businesses. Another center utilizes direct mail solicitation and membership drives.

The degree to which centers could determine costs of services and activities (total program costs, costs by funding source, service component costs, average cost per service and per individual served) was not as consistent as the other fiscal management practices. Almost all centers reported being able to determine total program cost (97%) and cost by funding source (95%), although only 92% actually provided total program budget information.

Even a center without any meaningful financial information system could presumably add up total monies spent and divide the total by their overall count of consumers to determine the average cost per consumer. A better indicator of a center's financial information capability is its ability to report total cost for individual service components. Such data collection would appear to be the minimum prerequisite for doing cost analysis, yet only 63% of projects reported they could determine costs by service component.

Determining the cost per service unit delivered and the cost per consumer requires not only good financial data on expenditures by service component, but also data on the actual amount of the service provided (e.g., numbers of consumers given a service, numbers of service units provided to individual consumers or overall). Many of the centers which could provide cost per service data apparently did not have corresponding systems in place for tracking clients and services. Thus, while 83% of the centers offering a service were, on average across the 18 services, able to provide data on the numbers of consumers provided the service, and 79% could provide data on the units of service provided, less than half reported being able to determine costs per service unit (49%) or even per consumer (49%).

The center mail survey did not address the actual quality and capability of the centers' financial management systems nor of cost performance, other than to ask centers to provide aggregated data on costs and services. Center directors were asked only whether various practices and systems were in place. Pretests of the survey and the Advisory Panel indicated that to ask for more detailed data was beyond the capability of most centers and would impose a serious time burden on those which could comply. The findings of the survey and the on-site visits have borne out that cautious note; most centers cannot provide detailed financial data of the kind needed to evaluate the costs of alternative service and client-targeting strategies and program goals.

D. Findings

Two different indicators of practice were used in exploring which centers were most likely to have good financial practices and systems -- the centers' reported ability to collect cost data by program service area and generate data on cost per consumer. These indicators represented the kinds of data most likely to be useful to managers in improving program performance. There was also enough variability across centers in their reported practice on these indicators so that analysis was feasible.

Centers which were subcontractors to state VR agencies were significantly more likely to have good cost data systems than centers which were direct grantees. Thus, 56% of VR subcontractor centers had data systems permitting determination of cost by type of service, in contrast to only 23% of direct grantee centers. Similarly, 54% of centers under state VR agencies were able to determine cost per consumer, while only 29% of direct grantees could do so. Both of these observations may result because some state VR agencies provided the centers with well-established information collection and reporting procedures or required increased accountability from the centers.

There was a similarly strong relationship between the number of years of operation and the capability of a center's financial management systems; 79% of centers which had operated more than six years could determine cost by service, and 68% of these older centers could determine cost by consumer. In contrast, 52% of centers in operation less than four years could determine cost per service area, while only 27% of these centers could calculate cost per consumer. It would seem that the longer a center continued to operate, the more likely its financial information system would become more refined and useful for cost analysis and monitoring. An alternative interpretation is also possible -- perhaps centers lacking such financial management capability are more likely to lose their community support and funding, and thus "go out of business."

Centers which had computerized financial information systems were much more likely to be able to determine cost per service (70% versus 53% of centers lacking computerized systems), and were also more likely to be able to determine cost per consumer (55% versus 40%). Fewer centers were able to measure cost per consumer, even with computerized fiscal systems, because this capability requires computerization of consumer and service data as well, and the latter is much rarer among centers than is computerized financial data. Sixty percent of centers had computerized their financial data, while 37% had computerized their consumer data and only 22% had computerized their service data.

Financial management capability also appeared to increase when the budget of the umbrella agency was larger, the budget of the center was larger, a smaller percentage of the total center budget came from Part

B, and the total amount of Part B funding was smaller. Larger center and agency budgets make centers more able to afford good financial management information systems (including computerization), and also increase the incentive for overseeing agencies to insist upon good financial monitoring by centers. The smaller the Part B funding level, the more likely that a center is dependent on multiple sources of funding, which may demand greater financial accountability by center management. Other agencies overseeing a center also may be able to provide the center with financial information systems, reporting formats, and management routines to strengthen the center's management.

The standard and the various data elements are principally administrative requirements, rather than performance standards, and normally would be required by regulation. There is no effective way to monitor the quality and use of financial systems in place without the detailed program administrative reviews and audits that are customary on a periodic basis with other federally and state-sponsored programs. The determination of costs of services offers the greatest promise of affecting center performance, but is the least prevalent fiscal management practice among centers. If each center developed its own cost accounting system for service components, there would be major gains for center management and financial accountability. Such systems would be even more valuable if standard service categories and units of service were developed and adopted across the various centers.

STANDARD 12: EVALUATION

The Grantee and the centers shall conduct annual self-evaluations and shall maintain records adequate to measure performance on these Independent Living Center Evaluation Standards, including:

12.1 Documentation of the number and types of individuals served (age, disability or relationship to disabled individual, gender, living arrangement, ethnicity, services received)
12.2 Documentation of the types and units of services provided to individuals and the community
12.3 Documentation of individual outcomes
12.4 Documentation of community Independent Living impacts
12.5 Client intake, service planning, and progress reports
12.6 Management records, including financial, legal, administrative personnel, and interagency agreements
12.7 Consumer evaluation of quality and appropriateness of the center program

A. Description and Purpose of Standard

The rationale for this evaluation standard is that centers which seek to be effective organizations and to find the best ways to serve disabled people need to assess how well they are performing and how they might improve. This is more easily accomplished when the centers maintain a basic minimum set of records which make assessments in terms of each of the standards possible. This particular standard, then, is in part justified by the existence of the other standards.

B. Summary of Achievement

Almost all centers reported they were able to provide most of the documentation required by Standard 12 (see Table D-12-A). More than two-thirds of centers also report compliance with elements 12.3 and 12.4. However, the actual ability of centers to provide data suggest that the quality and accessibility of data being collected on consumer and community outcomes is somewhat less than centers report. There is also wide variation across the centers in the kinds of outcomes measured and the way in which such outcomes are measured, making any comparative analysis of center experience in achieving success with different kinds of consumers or service strategies very difficult. Most centers are beginning to measure consumer outcomes, however, and not just consumers served -- a major step toward improved management capability and

Table D-12-A

Percentage of Centers Reporting the Ability to Provide Nine Types of Documentation

Documentation	%
Unduplicated number and type of consumers served	99%
Consumer intake records	98
Consumer progress records	98
Written consumer service plans	96
Types and units of services provided	91
Individual and community IL outcomes	75
IL goal achievement by individual clients	75
Computerized client information system	37
Computerized service system	22

accountability. Evaluation in its present form is still generally based largely on the clinical perceptions by staff and board members on whether particular practices seem effective or not. Systematic evaluation would not be feasible in most centers given the limited data on consumers, costs, and units of service available by service component. Consumer evaluation of services appears to occur informally at best, with few consumers directly acknowledging such participation. However, this could reflect a bias as consumers may not always recognize questions eliciting evaluative comments as being service evaluation. Disabled consumer perspectives on service appropriateness are also being provided, of course, by extensive participation on the boards and staff of centers.

Virtually every center (99%) reported maintaining an independent count of the number of individuals with disabilities they serve. However, only 78% were able to report the total number of individual consumers over the last month for which data were available, or for the previous year, and nearly two-thirds indicated that they were estimating the number of total consumers rather than reporting from exact records. One-third of the centers were unable to identify the disability of over 20 of their consumers, and 20% had more than 100 consumers with unknown disabilities. Table D-12-B. lists the percentage of centers which were able to provide or estimate information on the number of consumers to whom they gave various services and the number of service units they delivered. Across centers, an average of 83% could report the number of consumers provided with a given service, while an average of 79% could specify the number of service units provided. A broader utilization of computerized data retrieval by centers might improve access to these types of statistics, as only 37% of the centers reported that their consumer records were computerized. Some centers cited lack of resources as a major barrier to improved data access, perhaps less in terms of the costs of computer hardware and software than in the staff time needed for training and implementation.

Almost all centers (91%) report documenting the types and units of services provided, but as indicated above, these reports do not always permit a center to provide data on service units or consumers given that

Table D-12-B

Percentage of Centers Reporting Levels of Services Provided

Type of Service	% of Centers Providing Data on		Most Commonly Used Unit of Service for Center Reporting Units
	# Consumers	# Service Units	
Advocacy	85%	76%	Hours (36%) Contacts (33%) 15 minutes (16%)
Independent Living Training	85%	81%	Hours (49%) Contacts (17%) 15 minutes (14%)
Peer Counseling	87%	79%	Days (40%) Minutes (26%) Rides/Trips (17%)
Legal Services	92%	67%	Hours (36%) Contacts (36%) 15 minutes (14%)
Professional Counseling	86%	77%	Hours (35%) Contacts (35%) 15 minutes (12%)
Other Counseling	87%	84%	Hours (45%) Contacts (28%)
Housing Services	83%	75%	Contacts (33%) Hours (27%) 15 minutes (18%)
Equipment Services	86%	77%	Hours (28%) Repairs/Equipment Loans (20%) Contacts (22%) 15 minutes (16%)
Transportation	77%	78%	Rides/Trips (36%) Contacts (19%) Hours (15%)
Recreational Services	85%	80%	Hours (36%) Contacts (22%) 15 minutes (14%)
Educational Services	77%	77%	Hours (35%) 15 minutes (28%) Contacts (21%)
Vocational Services	83%	79%	Hours (45%) 15 minutes (26%) Contacts (13%)
Communication Services	81%	81%	Hours (37%) Contacts (26%) 15 minutes (17%)
Attendant Services	85%	79%	Hours (43%) 15 minutes (22%) Contacts (17%)
Electronic Services	91%	82%	15 minutes (27%) Contacts (27%) Repairs/Equipment Loans (18%)
Family Services	89%	74%	Hours (41%) Contacts (21%) 15 minutes (15%)
I & R Services	73%	82%	Contacts (41%) Hours (24%) 15 minutes (15%)
Other Services	65%	89%	15 minutes (26%) Hours (19%) Contacts (16%)

service. Table D-12B includes the three most common types of units reported for each type of service used by at least 10% of the centers. Almost 40 different types of units of service were identified from the surveys received. In some cases the service was being provided but the data simply not being collected.

Most centers (75%) report that they document the level of independent living goal achievement by individual consumers, and that they issue an annual evaluation report documenting such individual outcomes. Again, however, for all but four of the 14 kinds of consumer outcomes probed in the survey, less than a third of the centers could provide data directly from records. These data were missing altogether for an average 14% of the centers, and about half were unable to access the data they did have and thus had to estimate outcomes. Difficulties in reporting data may have stemmed from the fact that most centers have not computerized their consumer records, but instead make periodic manual counts of consumer outcomes to produce annual reports.

As noted above, 75% of centers reported that they issued evaluation reports at least once a year documenting community as well as individual independent living outcomes and impacts. On average, 18% of the centers were unable to provide data on specific community impacts when asked about a range of 18 outcome areas on the survey. Roughly half of the centers which did report numbers of impacts indicated that they were estimating the numbers cited.

Nearly all of centers report maintaining consumer intake records (98%), written consumer service plans (96%), and consumer progress records (98%). Again, most of these records are not computerized, requiring manual tabulations. This may explain why only 83% of the centers offering a service were (on average across some 18 services analyzed) able to provide data on the number of consumers receiving that service.

No data could be uniformly collected on the development and use of key documents affecting the overall center's operations, such as financial, legal, administrative, personnel, and interagency records. Field interviewers did not experience any particular problem in gaining access to such documents during site visits, though the design of the field study did not require that such documents be consistently examined on site for availability and completeness. Field staff did gather a broad array of examples of different types of management records and documents. These represent a range of approaches and degree of sophistication.

The center survey did not ask if centers routinely gathered consumer evaluations of services and center activities as part of center evaluation processes. However, the consumer survey did ask whether the disabled consumer had helped the center by evaluating services. Only 7% of the responding consumers reported such participation in evaluation.

C. Findings

Two indicators of compliance with good evaluation practice were chosen for use in statistical analyses: variables indicating whether centers issued evaluation reports and whether they documented consumer goals. These indicators were chosen because centers varied widely in the use of these procedures and because the measures had intrinsic substantive interest. Evaluation reports reflect an organization's willingness to have its performance and evaluation capability reviewed by others in the community. Documenting consumer goals indicates recognition that different consumers will have different needs -- an approach particularly appropriate for independent living programs. Such docmentation also means that data will be generated which can be used for assessing performance in a systematic way.

Organizational characteristics were tested in bivariate analysis for their statistical significance in relation to the use of the two evaluation procedures described above. However, no statistically significant relationships were found, even at a .2 significance level. Method of receiving funding, budget size, years in operation, proportion of total funding from Part B, service area size, disabilities on staff or board, and free-standing status all made no difference in the use of these evaluation procedures.

However, computerization was a major factor facilitating evaluation. Of those centers with computerized service data systems, 92% had issued evaluation reports and 89% had documented consumer goals, in contrast to 70% and 72%, respectively, of those centers which had not computerized such data. Similarly, 88% of centers with computerized consumer data systems prepared evaluation reports, compared to 67% without computerized information; such computerization did not, however, make a statistically significant difference in centers' documentation of consumer goals.

APPENDIX E

MULTIVARIATE ANALYSIS

APPENDIX E

MULTIVARIATE ANALYSIS

In this section, we shall try briefly to summarize some additional procedures and findings of the multivariate analysis. The overall procedure involved regression analyses with separate and combined "blocks" of variables. Many different variables of conceptual interest and similarity were put into several different groups or "blocks."

First, there was a "block" of variables representing organizational factors. This block consisted of measures such as:

- whether or not the center was overseen by VR as a grantee;
- whether the center was operating as a private nonprofit entity (or as part of such a nonprofit entity), or whether the center was being operated as part of a government agency;
- the total amount of the center's budget;
- the percent of total funding coming from Part B;
- whether there was a disabled Board majority, a disabled center director, and a high percentage of disabled staff in the center;
- the extent to which the overall philosophy of the center, summarizing across a range of questions, reflected a consistent disabled consumerist orientation;
- whether the center was serving only a part or the whole of a state;
- how long the center had been operating;
- various measures of the quality of the financial management, evaluation, and program planning capabilities of the center;
- the proportion of center resources which the center was choosing to expend on achieving community change, rather than on direct and I&R services to individual consumers; and

- the proportion of overall consumers who received only indirect information and referral services (I&R) as a proxy for the direct service orientation of the center's overall program strategy.

These variables clearly are somewhat interrelated, though the particular measures chosen were selected in each analysis to minimize multicollinearity among the different variables.

A second block of variables that was assembled consisted of service factors, that is, measures of the specific services received by individual consumers. This block included measures such as:

- measures of whether or not consumers had received a particular type of service (when the consumer respondents were being analyzed), or whether a type of service was offered at a center (when the 121 centers were being analyzed). In all, 16 types of services were analyzable with the consumer survey, and 18 types with the center survey. In the analyses of the 121 centers, these variables were the only variables in the services block;
- measures of the intensity of overall service provision to the consumer proxied by the number of contacts the consumer had with the center;
- whether the consumer was being served at the center and in personal interaction with the center staff, or whether the consumer was being served principally at home or through phone contact;
- the total length of time during which the consumer had participated in and received services from the center;
- whether the consumer, in addition to receiving services, had been a participant in the center's administration, delivery, or evaluation of its services;
- whether the consumer had been served by center staff who were disabled and whether the consumer and center staff had shared the same disability; and

- whether the consumer had a single case manager to help coordinate and expedite services, or, alternatively, had been served by many different staff over time.

The degree of intercorrelation among these variables was not as high as might be expected because most centers offered a wide array of services, and most consumers typically would only need a few of those services. The largest intercorrelations were among the so-called "core services" (as defined in Standard 5) but even there, correlations between pairs of services rarely exceed .20 in the consumer data and .30 in the center data; the intercorrelations among most services is below .10.

The third block of variables consisted of characteristics of the clients or consumers. Variables in this block included:

- the primary disability of the individual, e.g., visual or hearing impairment, mental illness or retardation, orthopedic or other. With the analysis of the 121 centers, these measures of disability were the only variables in the "consumer characteristics" block. To avoid over-determining the equations, the orthopedic disabled group was used as the baseline (omitted) category;
- a summary measure of the severity of the disabilities possessed by the consumer (including, among other assumptions, that SSI recipients were always severe). The use of the SSI assumption could lead to an interpretation of this variable as a measure of income disincentive for the individual in trying to achieve employment gains;
- the age, sex, and minority racial status of the individual consumer;
- how long it had been (in years) since the onset of the disability, as a measure of how long the individual had had to become socialized to living with the disability and the dependency often associated with such socialization;

- the residential setting of the individual at the time of entry into the center services -- explicitly whether the individuals were living in any kind of supervised setting, or with parents, rather than living in the community by themselves and without parents in the household;
- whether the individuals had any past history of employment, as a measure of past skills learned for community integration and work;
- whether the individuals had completed the survey themselves or had had to have a parent or friend complete the survey, as a proxy for the risk that the questionnaire responses being interpreted as coming from the consumer might actually be the opinion or perception of some other nondisabled associate with all the possible biases and nonvalidity that might thereby arise;
- whether the individual was a current or former VR program client, and thus might be receiving supplemental rehabilitation services outside the center. This measure also may be proxying for the individual's motivation and overall feasibility of achieving major goals in independent living, since VR counselors informally appraise applicants for rehabilitation feasibility prior to acceptance for VR services and even prior to center referral for further diagnosis and evaluation; and
- whether the individual's motivation for seeking services was to increase their independence, rather than simply maintaining their current level of independence.

Again, there was relatively little intercorrelation among these factors, in part because such a small percentage of center consumers had any past employment history.

The above blocks of variables measuring organizational factors, service factors, and consumer characteristics were used in regression and analysis of covariance to assess their influence on a variety of dependent variables measuring program and consumer outcomes. The dependent variables obtained from the 121 center survey include:

Measures of Consumer Impacts:

- the total number of individuals assisted with housing modifications as reported by the center;
- the total number of individuals assisted with transportation system modifications and adaptations of the transportation barriers confronting individuals, reported by the center;
- the total number of individuals assisted in finding attendants as reported by the center;
- the total number of individuals receiving training in shopping skills (as an indicator of training in independent living skills), as reported by the center; and
- the total number of individuals placed into or obtaining employment, as reported by the center.

Measures of Community Impact:

- the total number of professionals in the community whom the center reported as having provided training concerning the special needs of the disabled, as a measure of community system impacts not necessarily related to specific consumers.

Measures of Cost Performance:

- the calculated cost per consumer provided direct services by the center. It is important to note that uniquely with this outcome measure, in contrast to the other 13 outcome measures analyzed, a positive (+) relationship for a variable is actually an undesirable outcome, indicating that costs increase when this variable is present or measured. Thus, in describing impacts for variables, positive associations will be described in the text as "negative outcomes."

The outcome measures used for the consumer respondents are all measures of consumer impact. They include:

- whether the individual had experienced a move toward a more independent living situation in the community;
- whether the individual had experienced any of a series of situational improvements in a more independent living situation, education, employment, transportation or income, and the total number of such improvements reported by the individual;
- whether the individual had experienced any of a series of personal and psychological gains, and the total number of such gains reported;
- whether the individual reported receiving any of a series of aids, benefits, and services through assistance from the center, and the total number of such benefits reported;
- whether the individual had reported any of a series of gains in knowledge concerning independent living and program benefits, and the total number of such gains in knowledge reported; and
- whether the individual overall reported that he/she had been helped in living more independently by the center.

The various outcome measures are surprisingly not particularly correlated with each other, as Table E-1 indicates. The different independent living outcomes are very different from one another. Consumers who pursue some outcomes may find other possible outcomes irrelevant to their needs or, alternatively, still of high priority. The relevance of different outcomes will depend on a consumer's particular situation and needs. Given this pattern, it is not surprising that variables will prove positively correlated with some outcomes, but negatively or noncorrelated with other outcomes. Outcome measures represent very different goals for consumers; the factors influencing successful impacts for the program upon some outcomes may be unrelated altogether to the program's helping achieve some other outcome. Indeed,

Table E-1

Intercorrelation Among Outcome Measures[a]

Center Mail Survey Outcomes

	(H)	(T)	(A)	(S)	(J)	(CT)	($)
(H) Housing	1.000	.496	.312	.053	.077	-.077	.108
(T) Transportation	.496	1.000	.225	.356	.089	-.155	.121
(A) Attendants	.312	.225	1.000	.056	.305	-.028	-.091
(S) Shopping	.053	.356	.056	1.000	.188	.067	.066
(J) Jobs	.077	.089	.305	.187	1.000	-.116	-.022
(CT) Communications	-.077	-.155	-.028	.067	-.116	1.000	.070
($) Costs	.108	.121	-.091	.066	-.022	.070	1.000

Consumer Mail Survey Outcomes

	(R)	(I)	(P)	(SKL)	(A)	(K)	(IL)
(R) Improved Residential Situation	1.000	.538	.241	.186	.104	.191	.259
(I) Situational Improvements	.538	1.000	.430	.433	.283	.447	.184
(P) Personal/Social Changes	.241	.430	1.000	.575	.332	.499	.255
(SKL) Gains in Skills	.186	.433	.575	1.000	.492	.721	.268
(A) Aids, Services	.104	.283	.332	.492	1.000	.457	.178
(K) Gains in Knowledge	.191	.447	.499	.722	.457	1.000	.266
(IL) Perceived Gain in Independent Living	.259	.184	.255	.268	.178	.266	1.000

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[a] Pearson Correlation Coefficients

it will sometimes prove true that when one outcome is relevant to a consumer, another outcome will ipso facto be not relevant to a consumer, and thus a service which positively contributed to the first outcome will appropriated not be provided to consumers having the other outcome as a goal. Thus, for example, the vocational services that might facilitate a consumer's getting a job are precisely the ones that would not be given a consumer seeking to move from an institution to a more supervised but community-based residential setting, because the latter consumers are not feasible for employment.

In doing analyses, the center outcome measures are run with the blocks of organizational characteristics, center services offered, and disabilities of consumers served, both separately and in combination, with the degrees of freedom somewhat hampered by the limited sample size of centers. A "short form model" was also tried where the model had a more limited number of independent variables in each block, and which was to be used when the blocks were being analyzed in combination. But analysis indicated no particular statistical gains with the short form, and it was dropped.

The consumer outcome variables were also run with the three blocks (center characteristics, services received, and consumer characteristics), separately and in combination, but the degrees of freedom were less constrained because of the almost 1,000 consumers for whom data was available on each variable. It should be noted, however, that since all the consumers are drawn from a subsample of 36 centers, the organizational variables in the consumer outcome analyses pertain solely to those 36 centers.

Variance Partitioning Analyzing Overall Blocks of Variables

In order to understand the larger influence of the conceptual dimensions underlying the various blocks of variables above -- organizational factors, services, and consumer characteristics, we used variance partitioning procedures. This involves running blocks separately and in combination, looking at the overall variance explained (principally using the coefficient of determination, i.e., R-square), and then sorting out how much of the variance explained is due uniquely to a particular conceptual dimension and how much is shared across dimensions.

The need for this kind of analysis with the blocks described above is ultimately laid out in the conceptual model at the outset of the report. It is logical to assume that the organizational characteristics of centers may influence both the kinds of consumers they choose to serve and are able to serve. Such organizational characteristics similarly may influence the service strategies adopted by the center, and thus affect the service mix offered. The characteristics of the consumers who become center consumers should also be influencing the kinds of services provided; the type of services a particular consumer received ideally would be tailored to their particular needs and to the goals of that consumer for particular independent living improvements. Outcomes should be influenced by all three of the conceptual dimensions, both directly and indirectly.

"Indirect" influences may need some explanation. It may thus be true, for example, that centers which are well run (e.g., have certain organizational characteristics) will select the right mix of services to offer, so that consumers are well served. The influence of the good management of the center on outcomes could thus be captured in statistical analysis by analysis of the impact of the services provided upon outcomes. To the extent that the right services are prescribed for consumers and are competently delivered with high quality because of the organizational characteristics of the center, this would be an "indirect influence" of the organizational characteristics.

"Direct" influences would take other forms. By having many disabled staff or a disabled director or Board majority, the center might have more understanding of how to work with the disabled, might inspire consumers with the role models presented by staff, might increase consumer motivation to succeed, and might be more aggressive in pushing for community change to accommodate the consumer. Or some kinds of centers might be more effective in inducing other community agencies to provide services to consumers or to change their ways of operation to accommodate the needs of the disabled. Such important influences on the community and ultimately on the outcomes achieved by center consumers might thus not come at all through direct center services to the consumer or even through the direct interaction of the organization with the individual consumer.

Some researchers mistakenly focus only on the unique contribution of services to outcomes, e.g., the impact once consumer characteristics are controlled. This approach is tantamount to assuming that if the services were not provided, the outcomes would still be achieved solely because of the consumer characteristics. A major bias is thereby created against finding services to be of use to consumers, that is as distortive as the common program claim that all outcomes are due solely to the intervention of the program's services.

Variance partitioning is an analytic procedure that seeks to identify what portions of the variance "explained" by different conceptual factors are unique to those factors and what portions are shared with other factors. The total explanatory or predictive power of a factor is the sum of its unique and shared variance explained, it represents the "maximum" causal influence of a factor. The "unique" contribution to variance explained represents the "minimum" causal influence. Only theory and not any form of statistical treatment can allocate "shared" contributions to variance explained among the different factors involved.

We use the term "causal influence" cautiously because this study does not include an experimental control group. The use of regression analysis does provide a quasi-experimental design, however, given the large numbers of consumers involved. The regression analysis basically compares the outcomes of consumers who received many services with those who did not receive a service at all, controlling for many other factors, so that the consumers are maximally comparable. It is reasonable to expect that receiving more services should make some difference in outcomes.

Table E-2 sorts out the influence of the "organizational factors" and the "services" blocks of variables. (The variance explained by a block is the sum of its unique and its shared contributions.) Organizational characteristics as a separate block can account for or "explain" between 27% (training professionals) to 58% (housing) of the variance in

Table E-2

Impact of Service and Organizational Factors On Consumer Outcomes

Outcome Measure	% of Total Variance in Outcome Explained by Combined Factors	Distribution of Explanatory Power: % of Variance		
		Explained Uniquely by Services	Explained Uniquely by Org. Factors	Shared Between Service and Org. Factors
Center-Reported Outcomes (N = 121)				
Obtained Housing Modifications	74.7%	16.7%	45.1%	12.9%
Learned to Use Transportation	47.5	15.1	29.6	2.4
Obtained Attendants	51.1	19.1	31.6	0.4
Learned Shopping/Household Skills	51.8	20.7	31.3	1.7
Obtained Employment	74.6	36.2	32.7	5.7
Professionals Trained about Disabilities	46.4	19.3	23.6	3.5
Cost Per Consumer Served	53.0	8.4	42.2	2.4
Consumer-Reported Outcomes (N = 990)				
Independence of Current Residential Situation	8.9	6.2	2.1	0.6
Situational Improvements	26.3	20.6	2.3	3.4
Personal/Social Changes	31.3	24.3	1.9	5.1
Gains in Skills	39.1	29.0	1.9	8.2
Aids, Benefits, Services	36.2	27.8	1.8	6.6
Gains in Knowledge	37.6	29.4	2.1	6.1
Client Self-Perception of Increased Independence	15.1	11.4	3.6	0.1

the different center survey outcomes, but from only 3% (residential gains) to 10% (skills) of the consumer survey outcomes.[1] The services variables explain between 11% (costs) to 42% (employment) of the variance in center outcomes, and from 7% (residential gains in independence) to 37% (skills) of the variance on consumer outcomes. Combining the variables, the total variance explained ranges from 9% (residential gains) to 75% (housing and employment).

With the consumer data, the services block explains three to four times more of the variance in outcomes in separate analysis than does the organizational block; the unique contribution of services is ten to 20 times as great as for organizational characteristics. In the centers' data, the amount of variance explained (total and unique) is large for both blocks, although usually the organizational block explains more of the variance in outcomes than the services block and sometimes much more (housing, costs). In short, both blocks of variables provide consistent and powerful explanations of the variation in outcomes across centers and consumers, but the impact of services is far greater with the consumer data.

The variance partitioning also reveals, however, that the degree of intercorrelation among the two blocks of variables is not that high. One way of seeing this is to look at the percentage of the total variance explained which is "shared" by the two blocks in combination (Table E-3). This percentage is always less than 22% of the total variance explained, and for more than half the outcome measures, less than 8%.

These patterns imply several things, consistent with the analyses earlier in the report:

- organizational factors are not that important in influencing the mix of services offered at a center and provided consumers. Rather, most centers are offering a diverse array of services, and are tailoring the services delivered to consumers' particular needs. This suggests that there really is an emergent model of what an "independent living services program" should look like in a community.

Table E-3

Extent of Variance Explained in Outcomes Which is Shared Across Blocks of Service, Organizational, and Consumer Variables

Outcome Measure	% of Total Variance Explained by Center Factors Which is Shared Between Services and Org. Factors	% of Total Variance Explained by Center and Consumer Factors Which is Shared Between Center and Consumer Factors
Center-Reported Outcomes (N = 121)		
Obtained Housing Modification	17.3%	4.6%
Learned to Use Transportation	5.1	8.8
Obtained Attendant	0.1	12.9
Learned Shopping/Household Skills	3.3	35.1
Obtained Employment	7.6	54.2
Profesional Training about Disabilities	7.5	6.5
Cost Per Consumer Served	4.5	4.2
Consumer-Reported Outcomes (N = 990)		
Independence of Current Residential Situation	6.7	5.6
Situational Improvements	12.9	22.8
Personal/Social Changes	16.3	20.3
Gains in Skills	21.0	19.4
Aids, Benefits, Services	18.2	12.9
Gains in Knowledge	16.2	17.4
Client Self-Perception of Increased Independence	0.7	10.9

*Center factors combine organizational and service blocks of variables.

- the numbers of overall outcomes reported by centers appear to be influenced by organizational factors, but this influence is much weaker when individual consumer outcomes are analyzed. This is most likely due to the smaller number of centers yielding organizational characteristics to the analysis with consumer data (N = 36) as compared to analysis with center aggregated data (N= 121). But it also raises the question of whether the center-level outcome variables are really measuring outcomes, or whether they are measuring the centers' reporting systems. While organizational factors do make a difference in terms of consumer outcomes, it is a much smaller and less important difference than is made by the actual services provided by the centers. (On the other hand, the impact of organizational factors upon consumer outcomes is directly comparable in magnitude to the impact of consumer characteristics);
- the services provided consumers have a very large influence on consumer outcomes. While this might at first seem obvious, it should be emphasized that most evaluation studies using comparable kinds of data and methods do not usually find such a significant influence for services. In many evaluation studies with large data sets, the diversity in services received by consumers is not as great as appears to be the case with the center program and the variation in outcomes with types of services has been much less. This suggests again that the centers tailor services according to the individual needs of consumers, rather than simply offering a fixed array of services to all consumers,.

Given the diversity in services and the high amount of variation in the outcomes explained by services, one might anticipate that there would also be a high intercorrelation between consumer characteristics and services. When this happens, it is frequently inferred that the influence of services is really just a mask for the influence of consumer characteristics. That is, certain kinds of consumers tend to do well and to improve. The services may just be indirectly reflecting the kinds of consumers being served, such that when consumer characteristics are controlled, the marginal contribution of services to the variance in outcomes which is explained becomes trivial. In this context, analysts often wonder whether had a true experimental design with control groups been feasible, it might have been found that the consumers even without services would still have done well.

To examine the influence of consumer characteristics, another round of variance partitioning was performed, this time sorting out the influence of consumer factors as a block of variables and the combined blocks of variables connotating services and organizational characteristics. We will refer to the combined blocks as the "center factors." Table E-4 presents the results of this variance partitioning.

One immediately observes that consumer factors explain, by themselves, a very small proportion of the variance in outcomes for all the outcomes measured with consumer data and for most of outcomes measured with aggregated center data. For most of these outcome measures, consumer factors explain less than 12% of the variance. Only with two and perhaps three center outcome measures, however, are consumer factors important predictors, and then only when shared variance is considered as well: with the measures of individuals placed in jobs (R-square of 7.3 unique + 44.4 shared = 51.7% of variance in the outcome), individuals taught shopping skills (31.3%), and individuals provided with attendants (14.6%).

That these three kinds of outcomes at the center level were predicted by consumer factors, but not the other outcomes, makes sense, because they are the center outcome measures precisely where one would expect service needs to be very differentiated. Other center outcome measures -- housing, transportation, community professionals trained, cost - may be either generically important for most consumers (e.g., finding an accessible house or having transportation arranged) or are not that related to consumer factors at all (e.g., general training efforts of other community professionals, the costs of running a

Table E-4

Impact of Center* and Consumer Factors on Consumer Outcomes

		Distribution of Explanatory Power: % of Variance		
Outcome Measure	% of Total Variance in Outcome Explained by Combined Factors	Explained Uniquely by Center Factors	Explained Uniquely by Consumer Factors	Shared Between Center and Consumer Factors
Center-Reported Outcomes (N = 121)				
Obtained Housing Modifications	78.3%	71.1%	3.6%	3.6%
Learned to Use Transportation	50.0	43.1	2.5	4.4
Obtained Attendants	58.2	43.6	7.1	7.5
Learned Shopping/Household Skills	61.5	30.2	9.7	21.6
Obtained Employment	81.9	30.2	7.3	44.4
Professionals Trained About Disabilities	49.6	46.3	0.1	3.2
Cost Per Consumer Served	54.9	50.7	1.9	2.3
Consumer-Reported Outcomes (N = 990)				
Independence of Current Residential Situation	12.4	8.2	3.5	0.7
Situational Improvements	31.2	19.2	4.9	7.1
Personal/Social Changes	32.5	24.7	1.2	6.6
Gains in Skills	42.2	30.9	3.1	8.2
Aids, Benefits, Services	38.0	31.3	1.8	4.9
Gains in Knowledge	41.3	30.4	3.7	7.2
Client Self-Perception of Independence	17.5	13.2	2.4	1.9

*Center factors combine organizational and service blocks of variables.

program). It must be admitted, however, that these weak outcome relationships would not readily have been a priori assumed at the outset. Thus, one might well have initially expected that certain kinds of consumers (e.g., those in wheelchairs or the blind) would find housing or transportation needs more burdensome than other kinds of consumers.

A second explanation of the low explanatory power of consumer factors with the center outcome data may be simply that the only kinds of consumer data available at the aggregated level for centers was data on the consumer's major disability. While that variable is highly explanatory in the context of VR, it may be that centers are generally serving such severely disabled consumers that, regardless of the type of disability, difficult problems are being presented. More consumer information might thus be needed in the centers' analyses than the type of disability to infer the relative difficulty or type of problems being presented. Yet, when such additional data on the difficulty associated with the disability is provided, as in the consumer survey, the overall explanatory role of consumer factors still remains small.

The sorting of the relative explanatory power of the consumer and center factors blocks of variables surprisingly indicates also that there is little shared variance explained. Table E-4 indicates that for each of the consumer outcome variables, where the data on consumer characteristics is far richer and more extensive, the percentage of variance explained in outcomes which is shared by the two blocks of variables is less than 9%. For most of the center outcome variables, the percentage is below 8%. The shared variance is high with the shopping (22%) and jobs (44%) outcome measures. For shopping outcomes, the shared variance is much less than the variance explained uniquely by the center factors. Table E-3 shows that the percentage of the overall variance explained which is due to shared variables is usually less than 23%. What is notable and consistent with decades of research on vocational rehabilitation is that the issue of shared variance is greatest by far with the jobs outcome measure. Few consumers in the Centers for Independent Living program obtained employment, but for those who did, there was a strong interaction between the individual characteristics and the services received in explaining the outcome. Even there, however, the center factors uniquely were able to account for 30% of the jobs outcome variance, half the total variance explained.

The larger implications of these patterns include:

- center factors and especially services are highly and uniquely important in shaping the outcomes reported by consumers in the centers for Independent Living program. (We emphasize services because the earlier variance partitioning showed services to be much more powerful a predictor of outcomes than organizational characteristics.) Though ultimately any rigorously definitive test of this conclusion requires a study using experimental design and control groups, the customary high correlation between consumer characteristics and services does not arise for the centers. Had this been true, one might question whether the effect of services may be just masking the effect of consumer characteristics. This strong and unique contribution of the services variables to explaining the variance in outcome variance in the center program is quite different from the patterns found in comparable applications of this methodology to large-scale national program evaluations for other populations and services. In analyzing VR services for the disabled, long-term care services for the aged, protective services for families and children, manpower services to the unemployed and disadvantaged, we have always consistently found a high degree of intercorrelation among consumer characteristics and services. Ultimately, experimental design was needed in those program areas to sort out the true influence of services. With this program,however, since the intercorrelation is low, the services do appear to have consistently important impacts on whether higher levels of outcomes are reported by consumers.

- The lack of high correlation between the center and consumer factors blocks also indicates that, while there is a large diversity of services within centers and a large diversity of services given consumers, there has not yet emerged a common service technology, whereby services are prescribed in similar ways to address a given problem posed by a consumer. Thus, while a common model of an independent living services program is emerging, in the sense of centers regardless of organizational structure providing a large and comparable array of services, centers internally and across the nation do not provide a consumer presenting a given set of circumstances (and thus presumably needs) with a comparable set of services.

This lack of a common service prescription has several possible explanations. One explanation is the centers and their staffs do not yet know what works best to solve certain types of problems, and thus are continuing to experiment even within centers with a wide variety of service approaches to addressing the problem. With more program experience, evaluation and research, a common knowledge should start to develop and thus a common technology may emerge. A second explanation could be that centers take seriously the mandate not to prescribe for consumers, but rather to respond to what individual consumers want. Thus, because consumers differ in their desires for services and understanding of how services may help them achieve different goals, there may be no strong pattern that consumers with common characteristics are going to be provided comparable services. In summary, then, all three conceptual dimensions -- organizational characteristics, services, and consumer characteristics -- independently and significantly influence center and consumer outcomes. But the strongest influence by far is from the services provided consumers.

The Impact of Individual Variables

We have reviewed at length in the body of the report the findings for individual variables concerning relationships to different outcomes. In Chapter V, we present summary tables of the numbers of outcomes for which thee were positive, negative, and no relationships. (This analysis counts a positive association of a variable with costs per consumer as a "negative outcome.") In Chapter IX, we present summary tables showing the significance of associations for each variable, and the signs of the relationship for those variables which were statistically significant. We also presented at the end of the chapter some bar graphs showing the magnitude of the Beta-coefficients (i.e., the standardized regression coefficients) for all significant variables.

In reporting the findings of the multivariate analyses, we have viewed as substantively important any relationship with a significance level of at least .20. This guards against Type I errors of "false negatives," where a variable is judged not to have a relationship which it in fact does. In exploratory research with experimental programs, Type I errors have high costs, especially when technologies for accomplishing the desired program goals are still being developed.

With one outcome variable, whether the consumer experienced an increased independence in their residential situation, regression analysis is clearly an inferior method for analysis because of the binary nature of the outcome variable. Logit or probit analysis would be preferrable. The inferences made about the importance of variables with regression analysis are usually the same, however, as with these other techniques. This is especially so if higher significance levels (.20) are used, counteracting the bias in estimation of the standard error with binary dependent variables by the least squares method. It is the magnitude of the relationship where the regression technique can yield misleading estimates, but such magnitudes are never stressed in our report in presenting the multivariate analysis. Also, the conventions in logit and probit for handling extensive missing data are still undeveloped (in contrast to regression methodologies); missing data for some observations was true of almost all our variables. Finally, if reviewers judged that statistical significance testing and regression analysis made our analysis harder to understand, the complexity for the lay reader would have been even greater had we added logit or probit presentations as well.

Finally, to alleviate any concern that the multivariate analysis is frequently reversing the findings of bivariate analysis, we have presented in Table E-5 the bivariate (correlation coefficient) and the multivariate (regression) relationship between each of the outcome measures and each of the four principal measures of consumer influence. These relationships were thought to be also of some independent analytic interest, given the controversial nature of the advocacy for consumer influence or even control. The table shows that significant bivariate relationships tend to remain significant in multivariate relationships,

Table E-5

The Impact of Consumer Participation/Influence Factors Upon Outcomes - Bivariate and Multivariate Analysis

Outcomes	Percent of Board Members Disabled	Center Director Disabled	Percent of Staff Disabled	High Scores on Overall Philosophy
Center-Reported Outcomes				
Housing				
bivariate	+	ns(-)	+	-
multivariate	+	ns(+)	+	-
Transportation				
bivariate	+	ns(+)	ns(+)	-
multivariate	+	+	ns(+)	-
Attendants				
bivariate	ns(+)	ns(+)	ns(+)	-
multivariate	ns(+)	ns(+)	ns(+)	-
Shopping				
bivariate	ns(-)	ns(-)	ns(-)	-
multivariate	ns(-)	ns(+)	+	ns(-)
Jobs				
bivariate	ns(-)	ns(-)	ns(+)	-
multivariate	-	+	+	-
Training Professionals				
bivariate	ns(+)	ns(-)	ns(-)	ns(+)
multivariate	-	ns(-)	ns(-)	ns(+)
Cost per Consumer				
bivariate	ns(-)	-	ns(-)	-
multivariate	ns(-)	-	ns(+)	-
Consumer-Reported Outcomes				
Housing More Independent				
bivariate	ns(+)	+	+	+
multivariate	ns(+)	ns(+)	ns(-)	+
No. of Situational Improvements				
bivariate	-	-	-	+
multivariate	-	ns(-)	-	ns(+)
No. of Personal/Social Changes				
bivariate	-	-	ns(-)	+
multivariate	ns(+)	ns(-)	ns(+)	ns(+)
No. of Skill Gains				
bivariate	-	-	-	+
multivariate	-	-	-	+
No. of Gains in Aids, Services, Benefits				
bivariate	ns(-)	-	ns(-)	+
multivariate	ns(-)	-	-	+
No. of Gains in Knowledge				
bivariate	-	-	ns(-)	+
multivariate	-	-	ns(-)	+
Client Perception of Living More Independently				
bivariate	ns(-)	+	+	+
multivariate	ns(+)	ns(-)	ns(-)	+

ns = not statistically significant at .20 level and even when significance vanishes, the sign of the relationship (+ or -) tends to remain the same. It is with statistically nonsignificant bivariate relationships that one will occasionally find a flip of the sign in multivariate analysis, and even then the multivariate analytically determined relationship is also usually statistically non-significant.

APPENDIX F

Descriptive Statistics for Typical Centers, Medians and Means

Table F-1

Services Provided by a Typical Center During Last Year

Service	Median No. of Clients Served	Mean No. of Clients Served	No. of Reporting Centers (N)
Advocacy	80	226	89
ILS Training	70	128	95
Peer Counseling	40	121	90
Legal	23	59	22
Professional Counseling	27	43	30
Other Counseling	30	63	59
Housing	55	117	82
Equipment	30	66	64
Transportation	57	148	62
Recreation	38	71	64
Educational	27	65	36
Vocational	30	77	43
Communication	25	90	52
Attendant	40	104	71
Electronic	11	62	10
Family Support	20	48	41
I and R	301	708	74
Other	69	176	24
Pct. I and R Only Clients	30%	37%	96
Total Direct Service Clients	282	516	120
Total Clients	495	961	118

Table F-2

Outcomes Achieved by a Typical Center During Last Year

	Median No. of Outcomes Achieved	Mean No. of Outcomes Achieved	No. of Reporting Centers (N)
Center-Reported Client Outcome			
Housing Modifications	12	24	93
Released from Institutions	10	20	100
Financial Benefits	30	62	32
Learned How to use Transit	20	59	101
Got Driver's License	2	5	57
Got Attendants	24	52	97
Got Readers	10	64	79
Referred to Services	68	154	99
Able to do Chores	20	37	98
Got Devices	22	56	97
Achieved Goals	10	25	72
Got Employment	10	18	84
Registered to Vote	18	97	73
Served on Boards, Councils	8	14	81
Other	16	28	25
Center-Reported Community Impacts			
Housing Units Made Accessible	13	22	83
Accessible Vehicles	2	29	64
Attendants Recruited	27	45	72
Readers Recruited	3	8	41
Interpreters Recruited	3	6	44
Additional Funding Secured	$11,588	$146,797	51
Agreements Established	4	10	85
Educational Resources Procured	2	7	54

Table F-2 (continued)

	Median No. of Outcomes Achieved	Mean No. of Outcomes Achieved	No. of Reporting Centers (N)
Jobs Developed	8	17	62
Communication Devices	4	10	59
Public Building Made Accessible	6	12	78
Curb Cuts Made	15	32	71
Brailled Information Installed	3	14	39
Parking Spaces Reserved	10	22	65
Brailled Elevators	2	6	51
Recreational Programs	3	12	79
Health Providers Trained	18	65	78
Other Providers Trained	19	73	84
Other	28	93	16

Table F-3

Characteristics of the Typical Center

	Median	Mean	No. of Reporting Centers (N)
Total Budget	$ 240,000	$ 323,182	111
Part B Funding Award	$ 130,216	$ 133,932	118
- Pct. Part B of Total Budget	58%	57%	111
Total Other Federal Funding	$ 51,650	$ 92,595	23
Total State Funding	$ 86,810	$ 129,767	67
- Pct. State of Total Budget	6%	16%	111
Total Local Govt. Funding	$ 35,000	$ 50,206	37
- Pct. Local of Total Budget	0%	3%	111
Total Private Funding	$ 24,753	$ 48,192	58
-Pct. Private of Total Budget	0%	6%	58
Total Other Funding	$ 20,000	$ 55,867	52
Budget of Larger Agency	58%	57%	111
Housing Part B Center	$2,250,000	$3,636,463	36
Years Center Has Been in Operation	5 yrs.	6 yrs.	121
No. of Board Members	12	12	121
- Those Disabled	6	6	120
- Pct. of Board Disabled	56%	49%	121
No.of Advisory Group Members	5	8	119
- Those Disabled	5	5	119
- % of Advisors Disabled	53%	44%	121
No. of Administrators	2	2	121
- Those Disabled	1	1	121
No. of Direct Service Staff	5	6	120
- Those Disabled	3	3	120
No. of Support Staff	2	3	120
- Those Disabled	1	1	120
No. of Total Staff	10	13	121
- % of Staff Disabled	50%	52%	121

Table F-3 (continued)

	Median	Mean	No. of Reporting Centers (N)
No. of Volunteers	6	14	120
- Those Disabled	4	8	120
- % of Volunteers Disabled	56%	57%	121
Clients Served			
Those with Visual Disabilities	14	51	112
- Pct. Visual of All	3%	11%	112
- Those Blind	6	42	112
Those with Hearing Disabilities	12	96	112
- Pct. Hearing of All	2%	7%	112
- Those Deaf	5	87	112
Those with Orthopedic Disabilities	87	210	112
- Pct. Orthopedic of All	21%	26%	112
- Those, Amputees	5	25	112
- Those, Spinal Cord	18	63	112
Those with Mental Illness	6	21	112
- Pct. Mental Illness of All	1%	6%	112
Those with Mental Retardation	6	14	
- Pct. Mental Retardation of All	1%	4%	
Those with Other Disabilities	27	67	112
- Pct. Other of All	6%	11%	
Those with No Disabilities	0	114	121
- Pct. with no Disabilities	0	8%	117
Those with Unknown Disabilities (usually I and R-only clients)	43	367	60
- Pct. with Unknown Disabilities	14%	31%	115